Making the invisible visible: Home care provided by parents of children with complex needs

by

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Declaration of Originality

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Statement of Co-Authorship

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Paper 2: McCann, D., Bull, R., & Winzenberg, T. (2015). Sleep deprivation in parents caring for children with complex needs at home: A mixed methods systematic review. *Journal of Family Nursing 21*(1):86-118.
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Paper 4: Home adaptation and other parental strategies when living with a child with Autism Spectrum Disorder: a photo-interview study (submitted to *Focus on Autism and Developmental Disorders*)
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Located in chapter 9.
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Statement of Ethical Conduct

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University.

Damhnat McCann

Abstract

Home is the preferred site of care for children with complex needs. While parents describe the positive benefits that the child with complex needs brings to their lives, the care of these children can have a significant impact on the family, the home and on the physical, emotional, and mental health of the parents.

Methods

The research presented in this thesis aims to make more visible the often invisible work undertaken by parents caring for a child with complex needs. The multi method program of research contains a series of individual studies covering the daily care requirements and impact on the home environment when living with a child with complex needs. The studies include: a systematic review of the daily time use of parents of children with complex needs; a mixed studies systematic review that provides a comprehensive overview of night care and associated sleep disturbances; a detailed time use study with 10 mothers of children with complex needs using a recoded version of the Australian Time Use Survey; a pilot study exploring the competence, enjoyment and value placed on childcare related activities by those 10 mothers; and a photo-interview study exploring home adaptation and other strategies used by parents living with a child with Autism Spectrum Disorder. The thesis is structured as a thesis by publication, with the individual studies written as complete papers.

Results

Several key findings emerge across the individual studies contained within the research program: 1) parents of children with complex needs carry a significant caregiving burden based on the amount and intensity of the care they provide; 2) the intensity of the care results from the type of care that some children require, but also from the fact that parents frequently undertake two childcare related activities at the same time or combine childcare related activities with other activities; 3) the vigilance associated with caring for a child with complex needs requires a more intense and constant level of supervision or monitoring than is normally associated with parenting; 4) parents enjoy activities associated more with parenting rather than the caregiving role and actively

dislike undertaking healthcare related activities with or for their child; 5) caring for a child with complex needs impacts on family relationships and the home environment. The story that emerged through these findings provided the context for a rethinking of the vigilance required by parents of children with complex needs, leading to a novel application of the concept of continuous partial attention to the care of children with complex needs presented as a published paper within the thesis.

Conclusion

Parents of children with complex needs provide a remarkable level of care, but this care takes a physical, mental and emotional toll on the parents and the family. The research presented in this thesis provides previously missing detail regarding key aspects of the parental caregiving experience and the impact on family and home life, and reinforces the fact that parents of children with complex needs continue to lack the level of support they require in order to incorporate an intense caregiving role into their lives and the lives of their families. Viewing the caregiving role of parents of children with complex needs through the lens of continuous partial attention contributes a better understanding of why these parents find the caregiving experience uplifting, but also draining and exhausting, and may lead to improved approaches to providing support for the parents.

Parents need to receive a break from their caregiving role to enable them to switch off, even briefly, from the responsibility that they carry. Finding a way to support these parents in a manner that emphasises the positives, reduces the burden in areas that they find most difficult, and strengthens family relationships needs to be a primary focus for researchers and health professionals involved in the care of children with complex needs and their families.

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Finally, to the many children with complex needs and their families that I have had the privilege and pleasure of nursing over the years. This work is for you.

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List of Abbreviations

AAQ – Amount of Assistance Questionnaire

ABS – Australian Bureau of Statistics

ASD – Autism Spectrum Disorder

ATUS – Australian Time Use Survey

CCBS – Child's Challenging Behaviour Scale

CCN – Child with complex needs

NDIS – National Disability Insurance Scheme

Chapter 1 - Introduction and overview

Home care with parents as the primary caregiver is the contemporary model of care for children with severe disabilities, chronic illness and complex needs (Ward, Glass, & Ford, 2014). For the parents who assume the majority of the care for these children, the role requires extraordinary physical, emotional, social and financial resources (Murphy, Christian, Caplin, & Young, 2007; Strunk, 2010). Parents emphasise the positive benefits that arise out of living with a child with complex needs (Greer, Grey, & McClean, 2006; Hobson & Noyes, 2011; Kearney & Griffin, 2001), but there is evidence of significant caregiver burden and stress associated with this caring role (Coffey, 2006; Gallagher, Phillips, Oliver, & Carroll, 2008; Nelson, 2002). This is due in large part to the relentless, unpredictable and uncontrollable nature of the care (Bourke-Taylor, Howie, & Law, 2010; Murphy et al., 2007) and the constant everyday tension between distress and enrichment that arises out of the experience (Carnevale, Alexander, Davis, Rennick, & Troini, 2006).

Care for children with complex needs was previously provided in hospitals and institutions until the 1960s when cost-containment policies, new medical technologies and a humanitarian philosophy encouraged a move into home based care with parents assuming primary responsibility for the care of their child (Brust et al, 1992). Today, the majority of children with complex medical needs are discharged home despite the fact that they require treatments and interventions that previously would only have occurred in hospital including oxygen therapy, tracheostomies, enteral feeding, intravenous infusions, suctioning and complex medication regimes (Elias & Murphy, 2012; Macdonald & Callery, 2008). Many parents are also caring for children with a range of behavioural difficulties, social and communication disorders and mental health needs (Australian Institute of Health & Welfare, 2008).

The economic value placed on the informal care provided by parents and other carers in Australia is estimated to be double the official Government spending (Australian Institute of Health & Welfare, 2007a). Despite this significant contribution, the home care of family members with chronic illness is largely invisible to institutional healthcare

providers and the general population (Jowsey, Yen, & W, 2012; O'Connell, O'Halloran, & Doody, 2013). Parents of children with complex needs are likely to be stressed, fatigued and not politically organised, making a coordinated public outcry difficult and reducing their visibility (McDowell & O'Keeffe, 2012).

Within this thesis, the often invisible care work undertaken by parents of a child with complex needs at home is rendered visible through studies that provide an in depth exploration of the daily time use of mothers of children with complex needs, the competence, value and enjoyment of the childcare activities undertaken by the mothers, and the impact on home when living with a child with Autism Spectrum Disorder (ASD).

This introduction provides the background to the research problem addressed in these studies and is divided into four main sections. Section 1 provides an overview of the population of children with complex needs. Section 2 provides an overview of the impact on parents when at least one of their children has complex needs and the various ways parental care provision is measured and described. Section 3 focuses on the impact on the family, and section 4 focuses on the impact on home when living with a child with complex needs. The chapter concludes with a summary of the thesis.

1.1 Background to the research population

Discrepancies that exist in the reported prevalence rates for children with chronic conditions and disabilities both within and across countries are likely to be due in part to inconsistencies in the definitions used to describe this population of children (Davis & Brosco, 2007). Despite this, there is a general acceptance that the population of children with complex needs is increasing (Davies & Carter, 2013). This is due to a number of factors that include, but are not limited to, increased life expectancy (Brooks et al., 2014; MacKenzie et al., 2014), increased long term survival for even very low birth weight infants (D'Amore, Broster, Le Fort, & Curley, 2011; Itabashi et al., 2009; Wilson-

Costello, Friedman, Minich, Fanaroff, & Hack, 2005), and an increased prevalence of ASD (Fombonne, 2009).

1.1.1 Prevalence rates internationally

There is currently no reliable estimate of the numbers of children with disabilities or complex needs worldwide due to differences in definitions and the way information is collected (World Health Organization, 2012). The lack of standardisation of the different categories and definitions of children with disabilities or complex needs makes it difficult to aggregate data and get reliable estimates of the numbers of children involved at the national and global level (Baxter et al., 2015; Blackburn, Read, & Spencer, 2007). Global prevalence estimates do exist for some conditions, but specific information relating to children can be hard to obtain. For example, the global population prevalence of Autism Spectrum Disorders (ASDs) is estimated to be 7.6 per 1000 or one in every 132 people with a peak in childhood, but a breakdown of actual figures is not available (Baxter et al., 2015). Prevalence data therefore tends to be presented at the country level.

Approximately 14.6 million children aged 0-17 years in the United States (19.8% of the population of children and 23% of households with children) are classified as having special health care needs and more than 5% of US children have a disability (5.1% of children aged 5-15 and 5.6% of those aged 16-20) (Child and Adolescent Health Measurement Initiative, 2012; Erickson, Lee, & von Schrader, 2012). Around 65% of the children with special health care needs experience more complex service needs than just taking prescription medication (Child and Adolescent Health Measurement Initiative, 2012).

There are 952,741 (7.3%) children with a disability in the United Kingdom (UK) (Blackburn, Spencer, & Read, 2010), with an estimated 770,000 children (1 in 20) aged less than 16 years (Contact a family, 2015). The numbers of children with a disability in the UK includes children with a longstanding (12 months or longer) illness, disability or infirmity who experience one or more significant difficulties or health problems (Blackburn et al., 2010).

1.1.2 Population of children with complex needs in Australia

In Australia, almost 1.5 million children aged 0-14 years (2 in 5 or 37%) have at least one long term condition that has lasted or is expected to last at least six months, the most common including asthma, allergy, vision complaints (myopia/hyperopia), behavioural and emotional problems and anxiety-related problems (Australian Bureau of Statistics, 2012a; Australian Institute of Health & Welfare, 2012). More than 288,300 children aged 0-14 years have some form of disability (Australian Bureau of Statistics, 2012a) and over half (57%) of children with a disability (4% of all children) have a profound or severe disability (Australian Bureau of Statistics, 2012a; Australian Institute of Health & Welfare, 2012). While the prevalence of disability in children is lower than in 2003 (7% in 2009 vs 8.2% in 2003), the numbers of children with a severe disability are not significantly different between those two time points (Australian Institute of Health & Welfare, 2012).

Tasmania is the smallest state in Australia, an island state lying to the south of the main Australian continent. A quarter of Tasmania's population lives with a disability, the highest prevalence in Australia (Australian Bureau of Statistics, 2013). This prevalence remains higher even if adjustments are made for the older population (Australian Bureau of Statistics, 2012b). Tasmania has the highest prevalence of children with disability in school (11.1%) in Australia, consistent with variations in disability prevalence amongst school-age children between the states and territories (Australian Bureau of Statistics, 2012b). This higher prevalence of children with disability occurs in the context of a state without tertiary paediatric acute care facilities and a lack of specialised paediatric services (Department of Health and Human Services, 2015).

While national figures may be estimates rather than definitive numbers, the prevalence rates of children with disabilities and chronic illness internationally and nationally within Australia describe a significant proportion of children living with at least one disability, illness or functional impairment, and a large number of parents and families providing care to support these children through their daily lives.

1.1.3 Defining the research population

A range of terms are used to describe children with a disability and/or living with a complex or chronic condition, in part because research and policy groups recommend different ways to conceptualise, define and measure both illness and wellness in children (Davis & Brosco, 2007). Children with disability are not a uniquely identifiable group, different operational definitions of disability classifying a child as disabled in one context, but not in another (Australian Institute of Health & Welfare, 2004).

Consensus and consistent usage has been achieved with some terms, in large part because they have been adopted by Government and policy organisations. For example, the federal Maternal and Child Health Bureau (MCHB) in the USA uses the term 'children with special health care needs' (CSHCN), defined as those children who 1) have or are at risk of a physical, developmental, behavioural or emotional condition and 2) require health or related services of a type or amount beyond that required by children generally (McPherson et al., 1998). This term is now widely and consistently used in national reporting data, policy documents and research from the USA and includes all children with a medical, behavioural or other health condition lasting ≥1 year and also resulting in one or more of five health consequences - using or needing more medical, mental health or education services than other children of the same age; using or needing prescription medication; having limitations in ability to do what most similar aged children are doing; using or needing special therapy such as physical, occupational or speech therapy; using or needing emotional, developmental or behavioural treatment or counselling (Davis & Brosco, 2007). The child may have one of the five health consequences, or a combination of two or more (Bramlett, Read, Bethell, & Blumberg, 2009).

The definition of disability used in Australian Government publications and data collection is based on the framework for the conceptualisation, classification and measurement of disability provided by the International Classification of Functioning, Disability and Health (ICF) (Australian Institute of Health & Welfare, 2003). Based on this framework, the national *Survey of Disability, Ageing and Carers* (SDAC) conducted by

the Australian Bureau of Statistics (ABS) defines a person as having a disability if they have 'a limitation, restriction or impairment which has lasted, or is likely to last, for at least 6 months and restricts everyday activities' (Australian Bureau of Statistics, 2012a p. 1). These limitations or restrictions might include (but not be restricted to): loss of sight and/or hearing; incomplete use of limbs or extremities; mental illness; speech difficulties; difficulty learning or understanding; restriction in physical activities; fits or loss of consciousness; disfigurement or deformity; difficulty breathing; long term effects of brain injury or damage; a nervous or emotional condition (Australian Bureau of Statistics, 2004). A chronic condition is classified as an ongoing physical or mental condition that is characterised by functional limitation and service use or need beyond that expected for routine care (Australian Institute of Health & Welfare, 2007b).

However, there still remains a lack of consistency over the way terms are used to classify children with additional care needs in the literature more generally. Technology dependent, medically fragile and children with complex needs have all been used to describe children requiring support from technology (see for example Carnevale, Rehm, Kirk, & McKeever, 2008; Carter, Cummings, & Cooper, 2007; Davies & Carter, 2013; Glendinning, Kirk, Guiffrida, & Lawton, 2001; Kirk, Glendinning, & Callery, 2005; Spratling, 2015). The technology referred to for these populations generally relates to medically complex care including assisted ventilation, Continuous Positive Airway Pressure (CPAP) or Bilevel Positive Airway Pressure (BiPAP), oxygen therapy, enteral feeding, intravenous infusions (including the use of central lines), dialysis, and complex medication regimes (Elias & Murphy, 2012; Hewitt-Taylor, 2005), rather than technology that may support a child in other ways such as assisted communication.

Research classifying children as disabled, living with a disability or having a chronic condition frequently uses a categorical approach, relying on specific medical diagnoses (Davis & Brosco, 2007). But not all children receive a definitive diagnosis despite having complex care needs and a high level of disability and impairment (McDowell & O'Keeffe, 2012). Using a non-categorical approach that focuses on the effect of the health condition on the child negates the need for a specific diagnosis (Davis & Brosco, 2007)

and instead focuses on the functional ability of the child and the level of care the child requires.

For the purpose of consistency, and to enable the inclusion of children with a wide range of conditions, disabilities, levels of severity and functional impairment, the term children with complex needs will be used in the research presented in this thesis unless otherwise indicated. This term includes those children reliant on technology for medical care needs (the context in which the term is most commonly used) but also includes children who require more complex care for a range of reasons, including chronic illness (with or without acute exacerbations), physical and intellectual disability, functional limitations, and diagnoses more commonly associated with behavioural rather than physical limitations.

The following sections provide a background to the research problem addressed within the thesis by providing a broad overview of the roles that parents assume in order to provide the care required for their child with complex needs and the impact of this care provision on the parents, the family and their home.

1.2 Parenting a child with complex needs: Impact on parents

Children with disabilities thrive when cared for at home by a loving family (Bourke-Taylor, Pallant, Law, & Howie, 2013). Parents describe the joy of parenting a child with complex needs and the positive benefits and unconditional love the child brings to the family (Case-Smith, 2004; Griffith & Hastings, 2014; Lester & Reid, 2007; Olsson & Hwang, 2003). Any progress that their child makes, however small, is a cause for celebration (Lester & Reid, 2007). But many parents also describe being worn down and mentally weary as a result of the unrelenting 24 hour per day, seven days per week care required by the child (Bourke-Taylor et al., 2010; Jordan & Linden, 2013; Steele & Davies, 2006).

Different conditions or diagnoses pose particular challenges for parents. Parents of children with life-limiting conditions can find it difficult to deal with the regular changes in symptoms in their child due to condition/disease progression, while others find seizures very difficult to manage (Malcolm, Forbat, Anderson, Gibson, & Hain, 2011). The long term nature of the medical care required post a transplant creates more stress for parents than a single surgical event (Williams, Eilers, Heermann, & Smith, 2012). Parents of children dependent on technology experience chronic sleep deprivation and poor quality of sleep due to the need to provide overnight care to their child (Feeley et al., 2014; Meltzer, Sanchez-Ortuno, Edinger, & Avis, 2015). Living with a child with ASD has been likened to 'walking on eggshells 24 hours a day' (Woodgate, Ateah, & Secco, 2008, p. 1079) or being in the eye of a storm (Schall, 2000). Parents of children with higher levels of behavioural and emotional problems experience greater caregiver strain (Crettenden, 2008).

Nicholas (1999) identifies three types of maternal caregivers: trapped caregivers – primary caregivers who resent the demands and restrictions of the caregiving role; adaptive caregivers – those who view their caregiving role as just one aspect of their lives; and embedded caregivers – primary caregivers whose identity is encompassed in the caregiving role. For some parents, caregiving becomes the entire, overwhelming focus in their lives, mothers finding it very difficult to separate from their child (Bourke-Taylor et al., 2010; Kirk et al., 2005; O'Connell et al., 2013). This is compounded by the fact that many parents are caring for more than one child with complex needs. In one large national UK sample for example, 10% of severely disabled children had a disabled sibling and 2% had at least two disabled siblings (Roberts & Lawton, 2001). One quarter of all children with disability live with one or more siblings with a disability based on 2004/2005 UK data (Blackburn et al., 2010). The familial recurrence of ASD increases the likelihood that families will have more than one child affected (Gronborg, Schendel, & Parner, 2013; Risch et al., 2014).

1.2.1 Time use of parents of children with complex needs

Time use research or studies containing time use estimates have been conducted with parents of children with complex needs over the last four decades, but despite the interest, there remains only a limited understanding about how parents spend their time and who they spent it with or for. Discrepancies in the classification and description of the tasks that constitute caring for parents of children with complex needs and variations in the way in which time use information is measured and collected within this population has led to substantial differences in the total time spent in childcare reported in research in this area (Crettenden, 2008). In particular, relatively little information is available regarding the amount of time parents spend in activities directly related to the additional care needs of their child with complex needs.

Chapters 3 and 4 contain published systematic reviews that provide a detailed summary of the time use literature that focuses on parents of children with complex needs (McCann, Bull, & Winzenberg, 2012; McCann, Bull, & Winzenberg, 2015). In brief, half of the published time use studies in the systematic review of daily time use (Chapter 3) contain only one broad category for childcare that encompasses all the care provided to a child with complex needs and other children in the family if applicable, or else measure only time spent in physical care (McCann, Bull, & Winzenberg, 2012). Healthcare related tasks are rarely separated out from other childcare tasks (McCann et al., 2012). This is despite the fact that much of the research is conducted in populations of children with significant healthcare needs. Despite these difficulties, what is clear from many of the more robust time use studies conducted with parents of children with complex needs is the significant amount of time that many parents spend providing child related care (see for example Crettenden, 2008; Crowe & Florez, 2006; Hartley, Mihaila, Otalora-Fadner, & Bussanich, 2014; Sawyer et al., 2010).

1.2.2 Role strain

> *Without me, our family would disintegrate. I act as liaison, advocate, secretary, nurse, taxi, physiotherapist, occupational therapist, speech and language therapist, teacher for the blind. And I get no status in society for any of it.*
>
> (Parent of a disabled child, quoted in Bennett, 2009)

Coordinating the care of at least one child with complex needs requires parents to assume multiple roles in addition to being the parent of their child, the care going well beyond normal parenting (Meltzer et al., 2015). Depending on the severity of the child's condition and their care needs, parents and carers may be regularly performing treatments and procedures that were previously only undertaken by healthcare professionals in a hospital environment (Leiter, Krauss, Anderson, & Wells, 2004). Parents describe members of the healthcare team teaching them required tasks and assessing their knowledge and technique (Swallow, 2008). But carers may be ill prepared for the caring role, particularly if the person in their care has rapidly changing circumstances or is deteriorating (Community Services & Health Industry Skills Council, 2014).

Long term monitoring of the adequacy of training received by parents can be poor, with potentially little awareness of the ongoing competence of parents to deliver relatively common treatments such as enteral feeding, despite such treatments significantly affecting the health of the child when performed poorly or inaccurately (Evans et al., 2010). Compounding this is the fact that the healthcare staff providing care for children with complex needs outside the acute care setting may not have received sufficient education and training to cope with this changing population (Hewitt-Taylor, 2005). Community nurses are apprehensive when approaching the care of sick children at home, due largely to a perceived lack of competence and training (Samuelson, Willén, & Bratt, 2015). Home health nurses in the USA are more accustomed to working with elderly patients than young children (Pizur-Barnekow, Darragh, & Johnston, 2011). There is little availability of skilled paediatric nurses in rural areas (Elias & Murphy, 2012). Making this more difficult is the fact that the care requirements for many children

requires intense training and knowledge, reducing the number of people able to safely care for the child (Yantzi, Rosenberg, & McKeever, 2007). This reduces the support available to the parents and the opportunities for them to relinquish the care of their child to family, friends and care workers.

While parents are taught how to be technically competent to undertake the caring role, the psychological impact on parents undertaking complex procedures with their own child may be overlooked (Glendinning & Kirk, 2000). A large proportion of the extra care required by children with disabilities involves daily care activities that may be less rewarding for parents than the time spent playing, reading or talking to children (Crettenden, 2008). Qualitative research describes the difficulties parents experience undertaking treatments and procedures on their own child and their struggle with witnessing what their child has to endure, particularly when the treatment causes the child pain or distress (Lester & Reid, 2007; Tong, Lowe, Sainsbury, & Craig, 2008). Parents also experience guilt for putting their child through painful procedures or treatments and for not always strictly adhering to treatment regimes, instead choosing sometimes to just be a parent (Bowie, 2004; Marr, Leonard, Torode, & Downs, 2015).

Despite these descriptions, relatively little is known about the range and types of tasks undertaken by parents caring for a child with complex needs and the importance and meaning that parents attach to these tasks. Plant and Sanders (2007) and Cant (1994) measured the stress associated with specific care activities. Gevir, Goldstand, Weintraub, and Parush (2006) measured the meaningfulness and enjoyment of activities, although only in the broad category 'activities with children'. Parents have also been asked to rate child related activities as fun or a chore (Lampropoulou & Konstantareas, 1998; Padeliadu, 1998). While these studies contribute to our understanding of parental perceptions, very limited information is available regarding the types of tasks valued most highly by parents and those they find the least enjoyable. There is also no research to date that measures parents' perceptions of their competence to undertake healthcare related tasks for their child with complex needs.

1.2.3 Health of parents of children with complex needs

In addition to managing their child's illness and coordinating the required resources for their child, the parents must also maintain their family unit and maintain themselves (Sullivan-Bolyai, Knafl, Sadler, & Gilliss, 2004). But maintenance of self is often neglected, the parents reducing time spent doing leisure activities and activities for themselves due to fatigue and in order to implement therapy and attend to the care needs of their child (Hatzmann, Peek, Heymans, Maurice-Stam, & Grootenhuis, 2014; Jarbrink, Fombonne, & Knapp, 2003; Johnson, O'Reilly, & Vostanis, 2006; Thomas, 2011). They also reduce the time spent doing exercise and go without treatments, including dentistry, due to the financial and time costs involved in caring for their child (Bourke-Taylor, Cotter, & Stephan, 2015; Fletcher, Markoulakis, & Bryden, 2012).

It is essential that parental caregivers remain healthy in order to provide the care required by their child and to support the well-being of the family unit (Foster, Kozachek, Stern, & Elsea, 2010). Reducing time spent on personal care and leisure activities, decreasing exercise and forgoing treatments while dealing with the stress associated with caring for a child with complex needs comes at a cost; poorer emotional, psychological, social and physical health reported in parents of children with complex needs compared to the general population of parents (Brehaut et al., 2004; Crettenden, 2008; Murphy et al., 2007; Raina et al., 2005). Higher caregiver burden in parents of children with intellectual disabilities is associated with higher levels of depression and anxiety (Gallagher et al., 2008). Parents experience back and shoulder pain as a result of moving and transporting a child with physical disabilities, especially as the child becomes older and bigger (Gibson, 2014; Murphy et al., 2007).

Unlike parents of typically developing children whose need for night-time attention reduces over time, parents of children with complex needs continue to have disturbed sleep in order to provide care (Bourke-Taylor et al., 2010; Morelius & Hemmingsson, 2014). Almost half of Australian mothers of a school aged child with disabilities in one study (49%) woke at least once, four or more nights per week to attend to their child, with 11% of the mothers never sleeping through the night (Bourke-Taylor et al., 2013).

In another study, 70% of mothers of children with profound intellectual and multiple disabilities woke at least once per night to care for their child (Tadema & Vlaskamp, 2010).

The need for overnight care and attention means that parents of children with complex needs experience chronic sleep disruption contributing to ongoing fatigue and mental exhaustion (McCann, Bull, & Winzenberg, 2015; Morelius & Hemmingsson, 2014). Sleep deprivation and/or poor sleep quality has been associated with poorer mental and physical health in mothers caring for children with complex needs (Bourke-Taylor et al., 2013; Gallagher et al., 2008; Lee, 2013; Meltzer et al., 2015). Mothers who experience greater sleep deprivation are also more likely to report body pain, a significant concern when considering the very physical tasks involved in caring for children with disabilities and functional limitations (Bourke-Taylor et al., 2013).

Wilgosh and Scorgie (2006) state that there is no clear evidence that the stresses encountered by families living with a child with complex needs are greater than those encountered by the average family. But this is not reflected in many studies, significantly higher levels of parental stress reported in parents of children with a range of conditions and disabilities including asthma, diabetes, intellectual disabilities, technology dependency and developmental disabilities (see for example Cousino & Hazen, 2013; Hullmann et al., 2010; Lee, 2013). High or clinically elevated stress levels have been reported in 75% - 87% of parents of children with ASD (Dykens, Fisher, Taylor, Lambert, & Miodrag, 2014; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008) and these stress levels are higher than that reported by families of children with other developmental disabilities, including children with intellectual impairment and behavioural problems (Hastings & Johnson, 2001). Mothers of adolescents and adults with ASD are three times more likely to experience a stressful event on any given day compared to mothers whose adolescent/adult child is typically developing (Smith et al., 2010).

1.3 Parenting a child with complex needs: Impact on family

In addition to having a significant impact on the parents who provide the majority of care, having a child with complex needs also affects the physical, emotional, social and financial health of a family (Gibson, 2014).

1.3.1 Economic impact

Worldwide, poverty and disability are strongly interlinked; poverty is a factor that increases the likelihood of disability, but also becomes a consequence (World Health Organization, 2012). Lower family earnings are reported in families with at least one child with ASD (Cidav, Marcus, & Mandell, 2012). Households that include a child with disabilities in the UK have a lower median income compared to those without, and for more than 20% of these families, the income is less than half the mean UK income (Blackburn et al., 2010; Contact a family, 2015). Almost half the single mothers caring for at least one child with ASD in a recent study had an annual income of $US25,000 or less and 79% earned $US50,000 or less annually, despite being a well educated sample including 43% with a bachelor's degree (Dyches, Christensen, Harper, Mandleco, & Roper, 2015). Caring for a child with disabilities creates a considerable financial burden for families in low income countries (Gona, Mung'ala-Odera, Newton, & Hartley, 2011; Griffiths, Dieye, Fleming, Hajjeh, & Edmond, 2012).

For many parents, caring for a child with complex needs results in a 'double whammy' – increased costs associated with the care needs of the child, but reduced capacity/opportunity to work, particularly when the employer is not willing or able to accommodate the increased leave requirements associated with the caring role (Bourke-Taylor et al., 2010; Green, 2007). Parents reduce their hours at work, do not return to work after maternity leave or quit work due to the demands of caring for their child with complex needs (Aitken et al., 2009; Busch & Barry, 2007).

The full cost of the needs of children should be taken into account when assessing the adequacy of the benefits and services provided by government to support parents caring for children (Ironmonger, 2004). This becomes even more important when

considering the level of care and expenditure on therapy, educational services, equipment, supplies, medication, admissions to hospital, respite care and complementary and alternative services by parents of children with complex needs (Bourke-Taylor et al., 2015; Busch & Barry, 2007; Landfeldt et al., 2014). More than a decade ago, the total additional expenditure for UK families with a child with severe disabilities was calculated at £97,450 per year, more than £40,000 of which was not provided by government or charitable sources and therefore needed to be found by the families (Curran, Sharples, White, & Knapp, 2001). Parents of children with ASD describe significant out of pocket expenses, in large part to pay for therapy, but also for special diets and home repairs (Fletcher et al., 2012; Raz, Lerner-Geva, Leon, Chodick, & Gabis, 2013; Twoy, Connolly, & Novak, 2007).

1.3.2 Impact on relationships

While the financial costs are significant and can cause severe hardship for families (Lester & Reid, 2007) there are other costs experienced by the families of children with complex needs. The relentless nature of the caregiving has an impact on the primary caregiver's relationships with their spouse/partner and may be positively correlated with marital strain (Larson & Miller-Bishoff, 2014; Risdal & Singer, 2004), although this finding is not consistent across all families. For some couples, intimacy and their relationship is negatively affected, while for others, having a child with complex needs brings them closer together and strengthens family relations (Bourke-Taylor et al., 2010; Gibson, 2014; Larson & Miller-Bishoff, 2014; Lester & Reid, 2007; Olsson & Hwang, 2003; Tong et al., 2008).

For many parents, caring for a child with complex needs alters the way they structure time together. Parents spend their nights apart or take shifts in order to constantly monitor their child to ensure they stay safe (Heaton, Noyes, Sloper, & Shah, 2006; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Thomas, 2011). Parents of children with ASD frequently spend social time apart so that one parent is always able to care for the child with ASD (Fletcher et al., 2012). Other parents take a tag team approach, splitting the care of children in order to better meet the needs of the child with complex needs and their sibling/s (Koch & Mayes, 2012). This dual parenting enables shared responsibility

for the child, thereby lessening the load (Rodrigues & Patterson, 2007). The arrangement only works, however, when two parents or an extended family are caring for a child. Significant numbers of children with complex needs are cared for in single parent families. In an analysis of almost 40,000 records from a UK database of families caring for at least one severely disabled child, more than one third of the children were being cared for by a lone parent (Roberts & Lawton, 2001). Caregivers of children with disability in Ohio, USA are disproportionately single or divorced compared to caregivers of typically developing children (Goudie, Narcisse, Hall, & Kuo, 2014). Single parent families were overrepresented in families with children with intellectual disabilities in a sample of Swedish families (Olsson & Hwang, 2003).

Having a child with complex needs in a family affects extended family members as well as parents (Miller, Buys, & Woodbridge, 2012). Having a child with ASD is associated with deceased family quality of life (Karst & Hecke, 2012). However, despite the difficulties, many families of children with complex needs display normal family functioning, although there is a greater negative impact on family functioning when the child has a more severe chronic condition and greater functional limitations (Rodrigues & Patterson, 2007). The basic underlying premise for parents of children with complex needs is that they are families first and as for all parents, the varied needs, interests and activities of all family members must be woven into a sustainable daily routine (McConnell & Savage, 2015). In reality, the needs of the child with complex needs often assumes priority, care of other children and choice of family activities orchestrated around the high care demands and/or restrictions of the child with complex needs (Johnson et al., 2006; Koch & Mayes, 2012; Nicholl & Begley, 2012).

1.3.3 Impact on siblings

Although parents strive to balance the needs of all of their children, in many families, less time is available to siblings and less attention paid to them due to the high care requirements of the child with complex needs (Fletcher et al., 2012; Gibson, 2014; Huang, Kellett, & St John, 2012; Knecht, Hellmers, & Metzing, 2015; Koch & Mayes, 2012). Medical symptoms in the well sibling may go unrecognised by parents due to the focus on the child with complex needs (Elias & Murphy, 2012). In some families,

extended family such as grandparents step in to provide a parenting role (Ravindran & Rempel, 2011). Siblings can exhibit jealously and resentment due to the amount of time and attention given to the child with complex needs and perceived preferential treatment of them (Huang et al., 2012; Tong et al., 2008). Aggressive or destructive behaviours in the child with complex needs results in more negative perceptions (Mandleco & Webb, 2015). But siblings also describe very positive relationships with their brother or sister with complex needs, displaying empathy and enjoyment toward them (Mandleco & Webb, 2015).

Siblings are aware of the fears and worries of their parents in relation to their brother or sister with complex needs despite the efforts of parents to shield them (Gibson, 2014). Children with complex medical needs and/or developmental issues comprise a significant percentage of the children admitted to hospitals (Elias & Murphy, 2012). This has a significant impact on parents who frequently remain with the child in hospital, but are also required to maintain a normal parenting role and organise care for children at home (Maltby, Kristjanson, & Coleman, 2003; Marr et al., 2015). Other children may need to accompany their parent and sibling with complex needs to hospital, particularly in an emergency, exposing the sibling to stressful, upsetting and frightening experiences (Carer Payment (child) Review Taskforce, 2007; Lester & Reid, 2007).

Parents also acknowledge that the other children may carry extra responsibilities due to their sibling's care requirements (Fletcher et al., 2012; Knecht et al., 2015; Koch & Mayes, 2012). Many siblings assume a caregiving role earlier in life to assist with the care of their brother or sister with complex needs despite a lack of appropriate training (Elias & Murphy, 2012; Gibson, 2014). Some parents deliberately shield siblings, limiting their involvement in the care of the child with complex needs (Koch & Mayes, 2012).

1.4 Parenting a child with complex needs: Impact on home

Moving the care of children with complex needs into the home requires a negotiation of the space and function between the home as a private domestic space, a workplace for carers and a place where complex care is occurring (Wilton & Hall, 2012). The home space may become an 'appropriated landscape' of care, the established meanings and routines of home disturbed due to the need to meet care needs (Dyck, Kontos, Angus, & McKeever, 2005; Moore, Anderson, Carter, & Coad, 2010). Homes of families living with a child with complex needs can be transformed by the presence of medical equipment required to fulfil the care needs of the child, resulting in a feeling of loss of ownership of the home (Glendinning & Kirk, 2000; Wray & Wray, 2004). This is accentuated by the presence of formal carers, compromising family privacy and comfort (Broberg, 2011; Coad et al., 2015; Kirk & Glendinning, 2004).

Parents try to keep their house organised by having a specific place for all the 'junk' (McGuire, Crowe, Law, & VanLeit, 2004). Homes are adapted to accommodate supplies and meet the clinical needs of the child (eg. installing a sink in a bedroom for a child on peritoneal dialysis), with medical equipment hidden or camouflaged so that it does not dominate the house (Carnevale et al., 2006; Swallow, Lambert, Santacroce, & Macfadyen, 2011). Children with physical disabilities need accessible ramps and other modifications to meet their mobility needs (Carnevale et al., 2006). Parents of a child/children with ASD and intellectual disabilities modify their homes (eg. high fences, locked doors and cupboards) to confine spaces within the home, keep their child (and other family members) safe, and prevent the child 'escaping' (Bourke-Taylor et al., 2010; Hodgetts et al., 2013; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011; Schall, 2000).

There are considerable costs involved in these home modifications (Every Australian Counts, 2015). An unmet need for home modification occurs in 10% of New Zealand families living with a child with a physical disability (Clark & MacArthur, 2008). Home modification was an additional (and for some unable to be met) expense for 43% of responders to a survey of a similar population in Scotland (About Families Project, 2013).

The lack of clarity around the type of home modifications that will be available for funding under the National Disability Insurance Scheme in Australia (Office of Parliamentary Counsel, 2014) makes it difficult to anticipate how much support families will receive, particularly if the child has an intellectual disability. Adaptations are difficult to arrange if the home is not owned by the family, a key factor when considering children with disabilities are more likely to live in rented accommodation and homes with fewer rooms compared to other children (Blackburn et al., 2010).

Despite a growing interest in the home aspect of home based care, there remains relatively little information generally on the practices of caregivers interacting with their children at home (Boles & Roberts, 2008). Most of the research to date has focused on children with physical disabilities and specifically the medicalisation of home and changes to the family's home environment when a child is dependent on technology (see for example Carnevale et al., 2006; Heaton, Noyes, Sloper, & Shah, 2005; Kirk & Glendinning, 2004; Kirk et al., 2005). Very little research has focused on the home environment in families living with a child with ASD (Pengelly, Rogers, & Evans, 2009). There is also a dearth of research exploring the type of home adaptations required by parents of children with complex needs (particularly children with an intellectual disability), the parameters placed around these adaptations, and the decision making processes involved.

1.5 Conclusion

The care provided by parents and families of children with complex needs mainly occurs at home, largely unseen and until fairly recently, largely unacknowledged. Considerable research has been conducted to date with parents and families of children with complex needs to better understand the caregiver burden associated with caring for a child with complex needs and the impact on family members, particularly parents and carers. However, significant gaps still remain in our knowledge of what is occurring in the home life of parents caring for a child with complex needs and their families. Time use research has been conducted in this area, but there remains only a limited understanding about

the range of activities parents are involved in over a 24 hour period. Relatively little information is available regarding the amount of time parents spend in activities directly related to the additional care needs of their child with complex needs and the care of other children in the family. Qualitative research has explored the experiences of parents caring for children with a range of conditions and disabilities and highlighted the tension between being both a parent and the person providing at times highly complex care for a child. But to date, very little research has measured how parents rate their ability to provide this care and their attitudes toward this care provision. Despite the fact that most of the care for children with complex needs takes place in the home, limited information is available regarding the impact that this home based care provision has on the home environment. While the medicalisation of home has been explored in recent years as the numbers of children dependent on technology living at home increases, almost no attention to date has focused on families living with a child with an intellectual disability or disorder.

1.6 Aims of the research program

The overarching aim underpinning the research program described in this thesis is to make more visible the often invisible work undertaken by parents caring for a child with complex needs. This aim covers both the daily care requirements and also the impact on the home environment when living with a child with complex needs.

The work presented in this thesis fulfils this aim and addresses some of the gaps in the research through a series of studies that:

- explore the time use of parents of children with complex needs;
- provide a detailed overview of the range of daily activities undertaken by the parents;
- measure the level of competence, importance and enjoyment that parents assign to healthcare related tasks undertaken for their child;
- explore parental strategies, including home adaptations used by parents when living with a child with ASD

1.7 Thesis summary

The thesis is presented in the format of a thesis by publication. Three chapters (Chapters 3, 4 and 9) contain a paper published in a peer reviewed journal, one chapter (Chapter 7) contains a paper accepted for publication and one (Chapter 8) contains a paper submitted to a journal and undergoing the review process.

The research is divided into three distinct sections:

1) Background to time use research with parents of children with complex needs (Chapters 3 and 4)

2) Caring for a child with complex needs (Chapters 5 – 7)

3) Impact on home when caring for a child with complex needs (Chapter 8).

Additional chapters describe the research methods used (Chapter 2) and present a new theory that provides an alternative lens for viewing the home care provided by parents of children with complex needs (Chapter 9). In the discussion chapter (Chapter 10), the research findings are summarised and integrated and discussed in the context of improving support for parents of children with complex needs.

1.7.1 Chapter 2: Methods

Chapter 2 provides an overview of the methods and approaches to research employed in the six individual studies that are included in the multi-method research program described in this thesis. The inclusion of a methods chapter was viewed as an important aspect to provide a clear and coherent overview of the variety of methods used in the individual studies, why these approaches were chosen, and how each of these studies contributed to the aim of the thesis and the overarching multi-method research program that underpins this body of work.

1.7.2 Chapter 3: Time use systematic review

Chapter 3 contains a systematic review of studies (published articles and theses) that measure the daily time use of parents of children with complex needs. The findings provide contextual background information for the primary research studies presented in Chapters 5-8 and identify gaps in the existing time use research that are addressed in those studies.

The systematic review was published in *Journal of Child Health Care* in 2012. A brief update summarising the findings from relevant time use studies published since the systematic review was conducted is provided in an additional section at the conclusion of the chapter.

1.7.3 Chapter 4: Sleep deprivation in parents of children with complex needs

Chapter 4 contains a mixed studies systematic review of published research measuring the time spent providing care during the night by parents of children with complex needs and describing the impact this care provision has on parental sleep length. Articles measuring time spent asleep or in overnight care provision and studies that include descriptions of sleep quality, length, or parental fatigue are included.

The systematic review was published in *Journal of Family Nursing* in 2015.

1.7.4 Chapter 5: Recoding the Australian Time Use Survey

Chapter 5 details the process involved in adapting the coding structure of the Australian Time Use Survey (Australian Bureau of Statistics, 2008) in order to extend the data collection potential of the tool for use in the time use study described in Chapter 6. The tool itself was only minimally changed, but interviews with key informants underpinned a restructuring of the data coding system for the tool to enable a detailed exploration of the activities undertaken by parents caring for a child with complex needs. It is this process that is described in chapter 5.

1.7.5 Chapter 6: Time use of parents of children with complex needs

Chapter 6 is a description of a time use study conducted with 10 mothers of children with complex needs using the Australian Time Use Survey (ATUS). The aim of the time use study was to describe the time use of parents of children with complex needs over two 24 hour periods. The additional coding options developed for the ATUS (described in Chapter 5) are used to enable a detailed analysis and description of the types of childcare activities that parents undertake for their child with complex needs and for other children in the family, with a focus on healthcare related tasks. This detailed analysis addresses existing knowledge deficits with regard to the specific types of activities undertaken by parents, previous research in this area tending to describe parental time use (particularly childcare related tasks) in broad categories.

The time use study is presented as a complete extended paper, following the format of the other primary research studies contained within the thesis.

1.7.6 Chapter 7: Competence, value and enjoyment of childcare related activities

Childcare related tasks taken from the diaries completd by the mothers in the time use study (Chapter 6) form the basis for a pilot study exploring the competence, value and enjoyment of childcare related activities for mothers of children with complex needs that is presented in Chapter 7. The Occupational Questionnaire is used to explore the competence, value and enjoyment of childcare related activities at the task level and within broader subcategories, enabling a differentiation between maternal attitudes toward categories of childcare related tasks undertaken for children with and without complex needs.

This paper was accepted for publication as a brief report in *Journal of Pediatric Nursing* in October 2015.

1.7.7 Chapter 8: Changes to home when living with a child with ASD

Through the process of undertaking time use research with mothers of children with complex needs and reviewing the existing research in this area, it became apparent that there was a significant knowledge deficit with regard to the home environment for families living with a child with complex needs, despite the fact that home is the site where the majority of care provision occurs. Discussions with a colleague (Dr Ceridwen Owen), an architect who had previously used photo-interviewing to explore the concept of home, identified a cross disciplinary area of research interest. This discussion led to a small photo-interview pilot study exploring home life for families of children with ASD, with an emphasis on home adaptation and modification. While there is a growing body of work with an emphasis on changes to the home environment experienced in families of children who are dependent on technology, similar work in the area of children with an intellectual disability or disorder is largely absent. Our pilot study aimed to address this gap.

The paper presented in Chapter 8 focuses specifically on the strategies, including home adaptations, used by carers of children with ASD to better manage, accommodate and celebrate living with a child with ASD. It has been submitted as a paper for publication to *Focus on Autism and Other Developmental Disabilities* (November 2015).

1.7.8 Chapter 9: Is the vigilance continuous partial attention?

Key themes arising from the research program presented in sections 1-3 of the thesis (Chapters 3-8) led to the development of an innovative new theory to better capture the level and type of vigilance required by parents caring for a child with complex needs that is presented as a published paper in Chapter 9. This theory attempts to better explain the requirement for vigilance and the impact this has on parents caring for a child with complex needs. Continuous partial attention, a concept previously only discussed in relation to information technology, is suggested as an alternative lens through which to view the type and level of vigilance required by parents caring for a child with complex needs every day. This paper has been published as an advance online publication in *Child: Care, Health & Development* (August 2015).

1.7.9 Chapter 10: Discussion and conclusion

Chapter 10 is the discussion and conclusion chapter which integrates the findings from each of the individual studies contained within the multimethod research program, discusses these findings in the context of existing published research in the area and concludes with recommendations for practice. A key focus of Chapter 10 is the identification of approaches and strategies that can be used to better support parents caring for a child with complex needs. Particular focus is placed on support strategies that may be helpful if the level and type of vigilance undertaken by the parents is indeed a form of continuous partial attention.

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Chapter 2 - Methods

The work undertaken by parents caring for children with complex needs has been largely invisible to date. Revealing the nature and depth of this caregiving requires a research design that enables exploration from multiple perspectives in order to better understand the type and nature of the caregiving that is occurring and the impact this has on the home life of the parents and their families. Multi-method design is an approach that enables individual studies to be brought together in order to address a broad research aim. In this way, each individual study contributes findings that broaden understanding. This is a key reason for choosing a multi method approach for the suite of research that comprises this thesis.

This chapter provides an overview of the methods and approaches to research employed in the six studies included in the multi-method research program described in this thesis. The range of methods and research approaches used within the individual studies contained within the three phases of the research program are broadly described, although more detailed information regarding data collection tools and data analysis occurs in the descriptions of the individual studies presented throughout the thesis. The term 'children with complex needs' is used throughout the thesis as the umbrella term to describe the diverse populations and samples included in the various studies, including children reliant on technology for medical care needs (the context in which the term is most commonly used), but also children who require more complex care for a range of reasons, including chronic illness, physical and intellectual disability, functional limitations, and diagnoses more commonly associated with behavioural rather than physical limitations.

2.1 Multimethod design

There is recognition of the value of taking a mixed methods approach to research with families of children with complex needs due to the need to identify the real-life challenges experienced by these families (Bourke-Taylor et al., 2013). A recent pilot study exploring sleep issues in parents of children with cerebral palsy confirmed the need for a mixed methods approach in future studies (Petersen, Harvey, Reddihough, &

Newall, 2015). Making more visible the often invisible work undertaken by parents caring for a child with complex needs (understanding what the parents do and the impact this has on the parents and their families) is the aim of the research program described in this thesis. Addressing this aim is the reason for the selection of a mixed methods approach.

Mixed methods research is a research design that 'focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies' (Creswell & Plano Clark, 2007, p. 5). The central premise is that the combination of research approaches provides a more complete and comprehensive picture of a research problem or phenomenon than would be gained by using either approach on its own (Creswell & Plano Clark, 2007; Doyle, Brady, & Byrne, 2009). Using a mixed methods approach in healthcare provides data that can be effectively used by the decision makers who determine healthcare policy (Doyle et al., 2009). The mixed methods approach used in this thesis is multimethod design, whereby a number of linked but self-contained quantitative and qualitative studies with different data collection methods form essential components of one research program (Hunter & Brewer, 2003; Morse, 2003). A strength of using a multimethod design is that it allows for different perspectives to be provided on a phenomenon, the interdependent studies together providing a more comprehensive picture than could be provided through a single study (Morse, 2003).

Addressing the broad aim of making more visible the often invisible work undertaken by parents caring for a child with complex needs requires a measurement of how parents of children with complex needs spend their time. However, this information needs to be placed within the broader context of how parents experience and view this time use and how living with a child with complex needs impacts on the home life for families. Multimethod design enables a comprehensive exploration of these phenomena. The separate analysis of the qualitative and quantitative data in the individual studies contained within this thesis allows the full development of the findings from each study and the use of both forms of data to develop, as well as test and support, the overall conclusions of the research program (Maxwell, 2015).

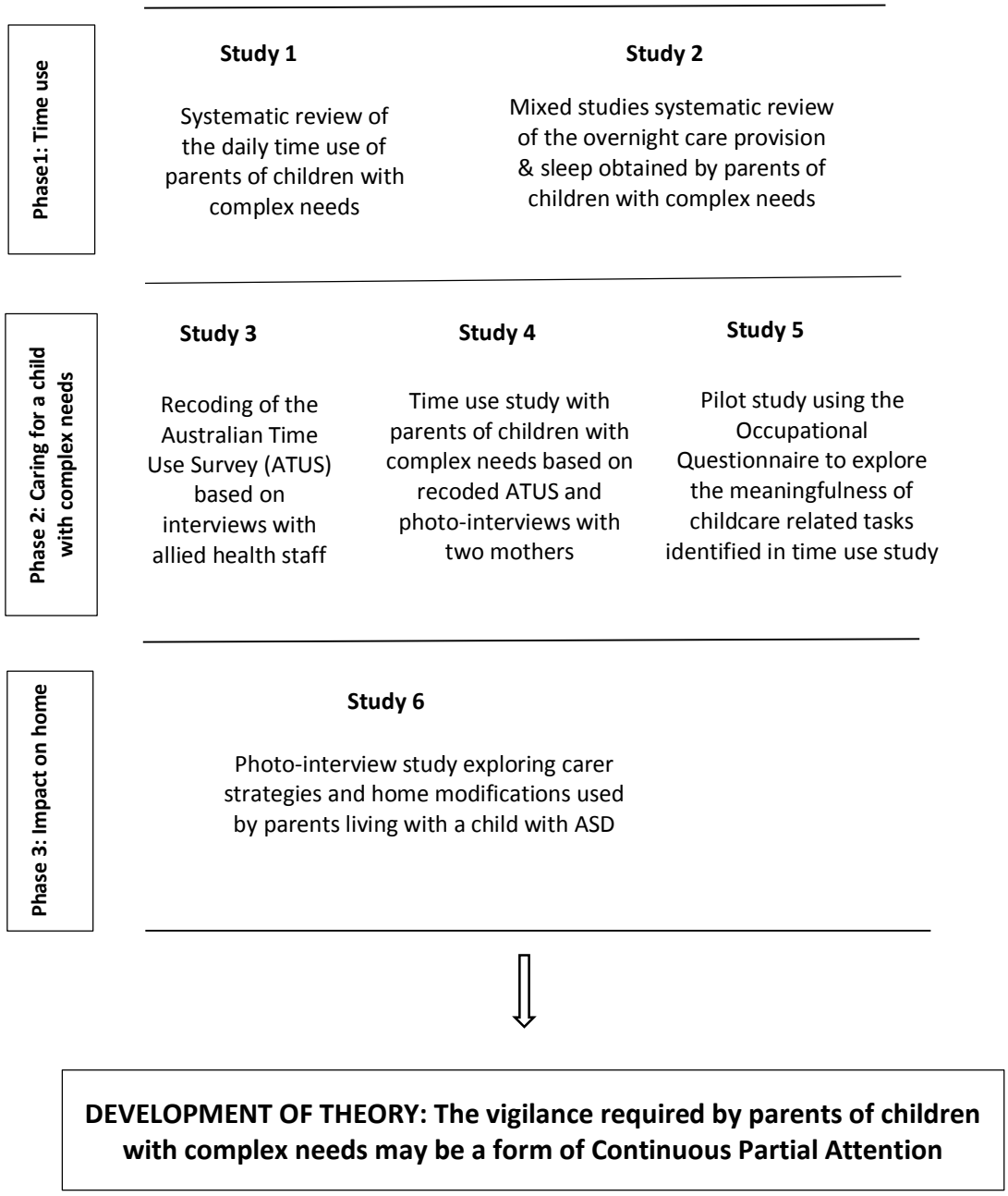
All projects in a multimethod design are complete in themselves. The projects are planned and conducted to answer particular sub questions that address the overall research question or aim (Morse, 2003). The six studies comprising the research program presented in this thesis can be viewed as separate entities. A number of them have been published as stand-alone articles. When taken as a whole however, the studies provide a detailed and multifaceted picture of what is occurring in the home lives of parents of children with complex needs. This integration of the findings from the individual studies has led to the development of a substantive theory (see Chapter 9) that provides a new understanding of the type of vigilance required by parents caring for a child with complex needs and is a key outcome of this research.

2.2 Methods of data collection

A central tenet of multimethod design is ensuring that the method for each project is kept intact and respects the assumptions, approaches to sampling and treatment of data that accompany that method (Morse, 2003). This tenet is applied throughout the studies in this thesis. The methods of data collection and analysis for each of the separate studies are chosen based on the aim of the study and the particular research question/s being asked.

The research program contains three distinct phases (see Figure 2.1). Phase 1 is comprised of two systematic reviews describing the time use of parents of children with complex needs during the day (Chapter 3) and overnight (Chapter 4). As well as providing a robust summary of current knowledge of this issue, these also provide the context for the three studies presented in Phase 2: a recoding of the Australian Time Use Survey ATUS (Chapter 5); a time use study with mothers of children with complex needs using the recoded ATUS (Chapter 6); and a pilot study measuring maternal enjoyment, competence and knowledge of childcare related tasks identified in the time use study (Chapter 7). Phase 3 is a photo-interview study that broadens the understanding of home based care by exploring the impact on home when parents are caring for a child with Autism Spectrum Disorder (Chapter 8). The three phases of the research program culminate in the substantive theory presented in Chapter 9.

Figure 2.1: Overview of the multimethod research program exploring the home care of children with complex needs presented in this thesis



2.2.1 Phase 1: Time use background

Phase 1 of the research program consists of one quantitative and one mixed studies systematic review. These systematic reviews provide a rigorous overview of previous research describing the day and night care provided by parents of children with complex needs. An overview of the systematic reviews is presented here, with the full study details contained in the relevant published papers presented in Chapters 3 and 4.

2.2.1.1 Study 1: Quantitative systematic review

The quantitative systematic review was conducted to answer three research questions:

1) What is the daily amount of time that parents of children with complex needs spend in the care of their child or children?

2) What are the classifications of childcare and associated time requirements for parents of children with complex needs?

3) Are there differences in the daytime patterns of time use between parents of children with complex needs and the general population of parents?

A narrative approach to synthesis was used to analyse relationships within and between studies and provide an overall assessment of the robustness of the evidence (Centre for Reviews and Dissemination, 2009). Although a meta-analysis was considered, the methodological differences in the studies included in the systematic review meant that this was not possible. Time use data was extracted from each study and summary statistics calculated for individual studies to show the variability in results within and across studies. Relationships between the characteristics of the 32 individual studies, their reported findings and the findings across the different studies were explored (Centre for Reviews and Dissemination, 2009).

2.2.1.2 Study 2: Mixed studies systematic review

A mixed studies systematic review was conducted to answer four research questions in order to provide a comprehensive overview of the night care and associated sleep disturbances experienced by parents of children with complex needs.

1) What is the total amount of sleep obtained by the parents of children with complex needs?

2) Are there differences in the sleep length between parents of children with complex needs and the general population of parents?

3) To what extent do the overnight health or general care needs of a child with complex needs affect the sleep experience of their parents?

4) What is the impact of sleep disturbance on the daily functioning of parents of children with complex needs?

Choosing a mixed methods approach for the second systematic review enabled in depth descriptions of sleep disturbance and the impact this has on parents and families. The information contained in the qualitative studies provided a real life context for the measurements of total sleep, amount of time awake and number of sleep interruptions obtained from the quantitative studies. Mixed studies reviews combine the power of stories and the power of numbers (Pluye & Hong, 2014). This was the key reason for selecting this approach for this systematic review.

The Mixed Methods Appraisal Tool (MMAT) for appraising the quality of studies included in a mixed studies systematic review (Pluye et al., 2011) was used to assess eligibility for inclusion in the review. The MMAT is an efficient tool for appraising methodological quality and its use overcomes the difficulty of otherwise needing to use a variety of critical appraisal tools to appraise different designs (Pluye & Hong, 2014). It has been used in more than 50 mixed studies systematic reviews to date (Pluye & Hong, 2014; Souto et al., 2015). Its reliability is well established, although further improvement

in the reliability is recommended for two of the questions in the qualitative domain due to perceived ambiguity in the interpretation of these questions among reviewers (Souto et al., 2015).

The first two research questions were answered with data relating to sleep length and amount from quantitative or mixed method studies. The remaining research questions were answered using data from qualitative, quantitative and mixed methods studies. The analysis of the quantitative and qualitative data was based on a segregated design[3] (Sandelowski, Voils, & Barroso, 2006). A narrative approach to synthesis was used to synthesise the findings of the included quantitative studies and explore and analyse the relationships within and between these studies (Centre for Reviews and Dissemination, 2009). The quantitative studies included in the systematic review were too methodologically diverse to conduct a meta-analysis. Narrative synthesis provided a robust approach to synthesising the evidence with the addition of summary statistics to address the main research questions (Centre for Reviews and Dissemination, 2009). Framework analysis (Ritchie & Spencer, 1994) was used to extract and analyse the data from the qualitative studies. Framework analysis is a flexible, systematic and rigorous method of data analysis (Ward, Furber, Tierney, & Swallow, 2013). It is becoming increasingly popular as a method of data analysis for qualitative studies and systematic reviews, including reviews exploring the care of children with complex needs (see for example Kruijsen-Terpstra et al., 2014; Noyes, Brenner, Fox, & Guerin, 2014).

2.2.2 Phase 2: Caring for a child with complex needs

Phase 2 of the research program explores in detail the daily care provided by parents of children with complex needs. An overview of the studies comprising Phase 2 of the research program is presented here, with the full study details contained in Chapters 5, 6 and 7. The main aspect of Phase 2 is a detailed description of the daily time use of 10 mothers of children with complex needs across two 24-hour periods, based on an adapted version of the Australian Time Use Survey that has been recoded to enable a more in depth exploration of parental time use. Photo interviews with a mother of a

[3] A more detailed description is provided in Chapter 4

child with ASD and a mother of a child with Rett syndrome provides contextual information to support the time use findings. The meaning and enjoyment of child care related tasks described in the time use study is explored in a pilot study using the Occupational Questionnaire (Msall, Lyon, & Gray, 2004).

2.2.2.1 Study 3: Recoding the Australian Time Use Survey

Study 3 is a small descriptive study that underpinned the development of a framework of in-depth childcare related codes able to be used when analysing data collected using the ATUS. The broad categories and sub codes of the ATUS were retained, but additional layers of coding and activities specific to the care of children with complex needs were developed to enable greater detail to be obtained. These additional coding layers were incorporated into the coding structure of the 2006 ATUS (Australian Bureau of Statistics, 2008) and formed the basis for the detailed analysis undertaken in the time use study (Chapter 6). The childcare related codes developed during the recoding study can be found in Appendix 8.

The initial version of the childcare related codes was developed based on descriptions of childcare related tasks contained in relevant literature in the area. Validation of the codes and the development of the final version was based on information obtained through interviews with four allied health professionals. These allied health professionals had significant experience working with children with complex needs and their families.

2.2.2.2 Study 4: Time use study

The time use study addresses three main questions:

1) How much time do parents of children with complex needs spend in childcare related activities in a 24 hour period?

2) What types of childcare related activities are undertaken by parents of children with complex needs?

3) How does the time parents spend in childcare related activities for the child with complex needs compare to the type of activities and amount of time spent in childcare related activities for other children in the family?

A free form 24-hour time use diary adapted from the Australian Time Use Survey (ATUS) (Australian Bureau of Statistics, 2008) was the primary data collection tool. Time use diaries are widely accepted as being the most valid measurement instrument to record daily time use (Geurts & De Ree, 1993; Juster & Stafford, 1991). They produce data consistent with real behaviour for most activities, and are not subject to the misunderstandings, recall problems, altering tendencies or overestimation that may occur with other methods (Neimi, 1993). Self-reported time use diaries produce reliable & replicable results with correlation coefficients between 0.85 and 0.95 (Robinson 1999 cited in Crowe & Michael 2011). Childcare activities recorded using time diaries have a reliability percentage of 74% (Juster & Stafford, 1991).

Although time use diaries enable the collection of highly detailed data, the key difficulty with their use is the time and effort required by respondents to complete them, particularly when the respondent is an informal caregiver (van den Berg & Spauwen, 2006). It has been suggested that completing a free form time use diary – where participants write down all of their activities during a specified period of time (van den Berg & Spauwen, 2006) is too onerous for parents who are already busy caring for their child with complex needs (Crettenden, 2008; Gevir, Goldstand, Weintraub, & Parush, 2006; Padeliadu, 1998). Lack of time and the need to keep a diary were reasons given

by parents for choosing not to participate in a randomised controlled trial aimed at reducing childhood obesity (Barratt, Levickis, Naughton, Gerner, & Gibbons, 2013).

The parental burden associated with completing a free form time use diary has led some researchers to reduce the burden by using a pre coded time use diary in research with parents of children with complex needs (Crettenden, 2008; Johnson & Deitz, 1985). Parents find the use of a pre coded diary acceptable with regard to ease of use and length of time taken to complete (Thomas, Hunt, Hurley, Robertson, & Carter, 2011). The limitation with pre-coding however, is the restriction this places on the respondent, all activities having to fit within the preordained codes. Detail regarding the specific tasks, for example healthcare related activities, that parents are undertaking is also lost. The importance of obtaining this information and the need to obtain detailed information regarding the type and range of child related activities undertaken by parents were the key reasons for using a free form diary divided into small time blocks, while acknowledging the burden a free form diary in five minute time blocks places on parents.

The participants all worked within the framework of the diary structure, although some participants provided considerably more detail regarding the activities in which they were engaged and who it was for or with. Unlike the usual approach to questionnaire or survey reporting, where no mention is made of comments scribbled on the survey instrument (Feilzer, 2010), particular attention was paid to additional comments (outside of the required information) that the mothers added to their time use surveys. Feilzer (2010) has described the value of including extra, unsolicited information obtained from comments that participants added to a public opinion survey in a study exploring the natural effect of providing crime information. The inclusion of the comments as additional qualitative data enabled the researchers to reflect on the limitations of the survey questions and qualify simplistic responses to very complex issues (Feilzer, 2010). Taking note of the additional comments added by the mothers to the time use questionnaires similarly helped to clarify responses that otherwise had the potential to be misinterpreted and provided the opportunity to obtain explanatory qualitative data by following up on key comments through phone calls or letters.

Additional information obtained through this process was used at the individual level when coding the time use diaries and provided the stimulus for lines of enquiry explored through other aspects of the research program.

Additional questionnaires used in time use study

In addition to the time use diaries, the mothers completed a demographic questionnaire designed for the study; the *Time Crunch Scale* (Robinson 1991); *Child's Challenging Behaviour Scale* (Bourke-Taylor, Law, Howie, & Pallant, 2010); and the *Amount of Assistance Questionnaire* (Msall, 1996). These questionnaires can be found in Appendices 3 to 7 and are described in detail in Chapter 6, sections 6.2.5.1 to 6.2.5.5.

2.2.2.3 Study 5: Meaningfulness attached to child care related activities

Study 5 is a pilot study incorporating data obtained from the time use diaries (Chapter 3). The primary aim of the study was to explore the meaning that parents attached to the child related activities that they undertook on a daily basis. There were three main research questions:

1) How do parents of children with complex needs rate their competence to undertake child care related activities, particularly healthcare related tasks?

2) How do parents of children with complex needs rate the importance of child care related activities?

3) What level of enjoyment do parents of children with complex needs attach to child care related activities?

The data collection tool for the pilot study was the Occupational Questionnaire, a self-report instrument measuring occupation with a focus on activity and volition (Smith, Kielhofner, & Hawkins Watts, 1986). The Occupational Questionnaire has previously been used with elderly persons and adults with rheumatoid arthritis and multiple sclerosis (Cahill, Connolly, & Stapleton, 2010; Forhan & Backman, 2010; Niva & Skär, 2006) but no reliability or validity information is available. No studies using the full

version of the tool with parents of children with complex needs was located. An adaptation of the Occupational Questionnaire was used with parents of children with disabilities and ADHD to assess meaningfulness of tasks but this was related only to the broad category *activities with their children* (Gevir et al., 2006).

2.2.3 Phase 3: Impact on home

Phase 3 of the research program focused on the home environment and adaptations occurring in the home lives of parents living with a child with complex needs, specifically ASD. An overview of the study is presented here, with the full study details contained in Chapter 8.

2.2.3.1 Study 6: Photo-interview study

Study 6 is a photo-interview study using self-directed photography conducted with seven parents that explores adaptations and modifications made to the home environment to accommodate living with a child with ASD. The aim of the study was to better understand the strategies, including home adaptations and modifications, used by parents living with a child with ASD.

The use of self-directed photography is a powerful research technique for connecting with and empowering interviewees that is widely used across social science disciplines (Bugos et al., 2014; Rose, 2012). In the photo-interview approach used in this study, the participants take their own photographs and then reflect on these in an interview, allowing deeper meanings to be explored (Whiting, 2015). This approach is particularly helpful when exploring everyday activities that participants may take for granted, providing a lens through which to understand how the participants see and interpret their world (Kantrowitz-Gordon & Vandermause, 2015) and enabling them to reflect on these activities in a way that may not usually occur (Rose, 2012). The use of self-directed photography enables data to be collected at a time that is convenient for the participants, minimising intrusion in their lives (Warren, 2005), but always happening in the reality of their experience (Wang & Burris, 1994). Crucially, self-directed photography provides an opportunity to empower participants, the taking and sharing

of the photographs providing them with a central role in the research process (Rose, 2012).

Photo-interview studies by their nature can be quite small, focusing in depth on a limited number of participants (Rose, 2012). Studies conducted with 10 or less participants are common (see for example Kantrowitz-Gordon & Vandermause, 2015; Reszel, Peterson, & Moreau, 2014; Silver & Farrants, 2015).

2.3 Ethical considerations

Approval to conduct the individual primary research studies that make up the research program contained within this thesis was obtained from the Tasmanian Social Sciences Human Research Ethics Committee.

All aspects of the time use research including the time use study, recoding exercise and pilot study assessing the meaningfulness attached to child care related activities were covered under one ethics application *H11241: Caring for children with complex needs* (see Appendix 1).

The photo-interview study exploring home modification in families living with a child with complex needs was approved under the ethics application *H0012135: At home with Autism: A study of the transforming meanings of 'home' from the perspective of carers of children with Autism Spectrum Disorder* (see Appendix 2).

A number of ethical safeguards were employed in the studies due to the potential for the subject matter to prove distressing for participants, the demands that participating in the research placed on already time poor parents, and to protect the privacy of participants and their children due to the collection of photographic data. For example, details about a free, carer specific counselling service were provided to all participants in information sheets and this was reinforced during formal interviews and informal discussions.

The balance between the need to obtain detailed data to enable comprehensive analysis of parental time use, and thus address a key gap in the current literature, needed to be balanced against avoiding causing additional stress to parents who already had significant demands on their time. Because of the importance of collecting detailed time use data, the use of a free form diary with short time intervals was essential and this, coupled with the acknowledged quality of the tool, was the key reason for using the ATUS. To balance this, only a small number of additional tools were used to collect other required data and short versions of tools were used were possible. For example, only the relevant section of the *Amount of Assistance Questionnaire* (Msall, 1996) was used to assess the functional capacity of the child.

There was also an awareness that while this program of research would require time and effort from participating parents, it would not provide direct assistance to the parents and would not immediately improve their existing support arrangements. The benefits of participation were therefore indirect rather than direct. However, this research does provide the parents with an opportunity to accurately document their time usage and commitments, describe their experiences to a wider audience, and provides a platform for the parents to increase awareness of their role caring for a child or children with complex needs by providing insight into what that role entails. During the formal interviews and informal chats that occurred when conducting the studies, the majority of parents indicated their desire to increase awareness within society and assist other parents of children with complex needs as a key reason for their participation, reinforcing one of the main reasons for undertaking this program of research.

The use of photo-interview in two studies[4] raised particular ethical considerations. The use of participant-generated photographs poses a specific challenge in relation to maintaining the confidentiality and privacy of the participants, particularly if the images are used when disseminating the findings from the research (Balmer, Griffiths, & Dunn,

[4] Photo-interview is used as the data collection method in the study exploring home adaptation in parents living with a child with ASD presented in Chapter 8 and also used in two interviews with parents of children with complex needs that provides contextual focus for the time use study presented in Chapter 6

2015; Bugos et al., 2014) as was the case for the study exploring home adaptation in parents living with a child with ASD presented in Chapter 8. The fact that the photographs had the potential to include children with complex needs, including children with a cognitive impairment, intellectual disability, or mental illness was a consideration that had to be specifically addressed when gaining ethical approval and during the conduct of the studies.

A number of safe guards were put in place to reduce the risks associated with using photo-interview. The parents had complete control over the taking and use of the photographs, including whether or not any of the photographs could be used for publication or presentation purposes (Balmer et al., 2015; Bugos et al., 2014). To facilitate this, a detailed consent form was designed for the study which gave parents the opportunity to identify photographs or parts of photographs they were happy to have included in publications and presentations and those that were only for use in the interview and for data analysis. Permission for the use of the photographs could be withdrawn at any time up to the completion of a publication or presentation (Bugos et al., 2014).

2.4 Conclusion

This chapter provides an overview of the methods and approaches to research employed in the six studies that are included in the multi-method research program described in this thesis. The following chapters (Chapters 3-8) detail the individual studies contained within the research program, either as a chapter of the thesis or as copies of articles published in peer reviewed journals. The findings from these individual studies provide the basis for the theory presented in Chapter 9 and are discussed in detail in Chapter 10.

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Chapter 3 - Time use of parents of children with complex needs

Chapter 3 is a systematic review of published articles and theses that measure the time use of parents of children with complex needs published in *Journal of Child Health Care* in 2012. While the heterogeneity of the included articles precludes meta-analysis, three main themes emerge from the narrative analysis. These are: 1) Parents of children with complex needs carry a significant caregiving burden that often does not reduce as the age of the child increases; 2) Supervision or 'vigilance' is a category of childcare that carries a particular time requirement for these parents; and 3) Parents of children with complex needs spend (sometimes considerable) time undertaking healthcare related tasks outside the 'normal' parenting role. The findings provide contextual background information in which to situate the primary research studies (Chapters 5-8) and identity existing gaps in time use research that are addressed in those studies. The published systematic review is followed by a brief update that summarises the findings from relevant time use studies published since the systematic review was conducted.

3.1 Details of publication

Citation: McCann, D, Bull, R & Winzenberg, T (2012). The daily patterns of time use for parents of children with complex needs: a systematic review. *Journal of Child Health Care*, 16(1), 26-52.

Statement of authorship: I conducted the systematic review, undertook the analysis and wrote the paper. Professors Bull and Winzenberg supervised the conduct of the systematic review and critically reviewed earlier drafts of the paper.

This publication has been cited 22 times to date (listed citations in Scopus) and ranks 8th on the list of most cited articles published in *Journal of Child Health Care. Journal of Child Health Care* has an impact factor of 0.875 and is ranked 63/108 in Nursing (SSCI), 66/110 in Nursing (SCI) and 99/119 in Paediatrics based on the 2014 Journal Citation Reports (Thomson Reuters, 2015). The findings of the systematic review were presented

in an oral presentation at the Winds of Change Conference, Council of Children's Nurses (Inc), Sydney 2011.

3.2 Published paper: The daily patterns of time use for parents of children with complex needs: a systematic review

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3.3 Additional time use studies not included in systematic review

The systematic review exploring time use in parents of children with complex needs was published in 2012. Six additional studies that include a quantitative measure of time use of carers of children with complex needs and have been published since the systematic review was conducted were identified (see Table 3.1). One additional study published in 2004 (Heyman et al., 2004) was also identified. This study did not contain key search terms relating to time use in the title or abstract and thus was not located in the initial systematic review search. These seven studies cover a diverse range of conditions including children with chronic conditions, with or without a gastrostomy tube (Heyman et al., 2004); cerebral palsy (Sawyer et al., 2011); Fragile X syndrome FXS (Bailey et al., 2012); Autism Spectrum Disorder ASD (Hartley et al., 2014); medically complex or technology dependent (Caicedo, 2014); chronically disabled (Şimşek et al., 2014) and a large survey of children with special healthcare needs (Miller, Nugent, & Russell, 2015).

Average total time spent in care ranged from 5.7 hours/day for children with chronic illness or who were technology dependent (Caicedo, 2014; Heyman et al., 2004) to 9.2 hours/day for children with ASD or sons with FXS (Bailey et al., 2012; Hartley et al., 2014) and 10 hours for children with a chronically disabling condition (Şimşek et al., 2014). Ranges for time spent in childcare related tasks varied widely, including 1- 168 hours per week for direct care for children who are medically complex (Caicedo, 2014) and 1-24 hours per day for children/young adults with fragile X syndrome (Bailey et al., 2012). Significantly more time was spent caring on weekend days compared to weekdays by mothers in the study by Sawyer and others (2011). The mothers in this study also spent significantly more time caring for a child who needed assistance mobilising compared to children who could mobilise without the use of a walker (Sawyer et al., 2011). It is unclear whether the reporting of 24 hours per day of care in the study by Bailey et al. (2012) relates to the need for parents to remain vigilant overnight in case care is required or describes active care provided by more than one parent or carer. None of the studies compared time spent in care of children with complex needs with a normative sample or control group of parents of typically developing children.

Three of the studies provided no breakdown of the childcare tasks (Hartley et al., 2014; Sawyer et al., 2011; Şimşek et al., 2014), categorising the care as caregiving activities or daily care time (see Table 3.1). Time spent in healthcare related tasks was specifically addressed in three studies (Caicedo, 2014; Heyman et al., 2004; Miller et al., 2015), although only two (Heyman et al., 2004; Miller et al., 2015) specifically referred to treatment related tasks or healthcare interventions. The need to provide technical care was significantly higher (149mins/day vs 48 mins/day) in children with chronic illness with a gastrostomy tube compared to those without, reflecting an additional 100mins per day of tube and skin care required for these children. This finding was not related to the child's functional status or age and was mirrored in the results for total caregiving (486 mins vs 198 mins) and non-technical care (283 mins vs 119 mins) (Heyman et al., 2004).

The broad findings from these seven studies confirm conclusions drawn in the original systematic review. A variety of methods for measuring time use are employed within the studies and there is a lack of consistency in the classification of childcare related tasks. Relatively little detail is provided regarding the types of childcare related tasks that parents spend time on during the day, although the studies by Heyman et al. (2004) and Miller et al. (2015) do add to the limited information regarding time spent in healthcare related tasks. Of interest is the finding by Miller et al. (2015) that medical homes are associated with lower odds of time spent coordinating care and in healthcare provision.

Similar to the findings of the published systematic review, there is wide within and across study discrepancies in the time spent in care, making it difficult to draw conclusions. But the studies do support key findings of the published review, namely that parents spend significant amounts of time during the day providing child related care, and that this occurs across a range of conditions and diagnostic groups. Despite these additional seven studies, greater detail regarding the time spent in different types of childcare related activities and the range of tasks being undertaken by parents each day is still required.

Table 3.1: Time spent in childcare by parents/primary carers (additional studies not included in systematic review)

Author/s	Sample*	Time use measure	Classification of childcaring	Caregiving time	Additional time expenditure findings
Heyman et al. (2004)	Maternal caregivers of children with chronic condition with gastrostomy tube GT (n=50) or without NGT (n=51)	Time estimate in interview - minutes of care provided over preceding two weeks (TC & NTC) or minutes care/week over last 3 months (HCM)	**1) Technical care TC** (assessing equipment, medication, care of tubes, skin care related to tubes/wounds, crisis care); **2) Nontechnical care NTC** (feeding, bathing, general skin care, toileting, mobility assistance, grooming, dressing, diseases related laundry/housecleaning); **3) Healthcare management HCM** (arranging care, finances, technology/care related education/training, travel & waiting)	**Total care (mins/day)** GT (486 ± 55); NGT (198 ± 31). **Mean times (± SEM): 1)** GT (149 ± 24); NGT (47 ± 11) **2)** GT (283 ± 38); NGT (119 ± 23) **3)** GT (52 ± 11); NGT (32 ± 6)	Significant difference (higher in GT) in time spent in total care and technical care (p<.0001) and nontechnical care (p=0.0001)
Bailey et al. (2012)	Caregivers (n=350) of children (n=191) and young adults (n=159) with fragile X syndrome (FXS)	Time estimate in survey	Care for FXS related needs. Examples provided: assisting with personal tasks; transporting to appointments; helping with activities/tasks; supervising unstructured leisure time	Parent of a son with FXS: 9.2hrs/day (range 1-24hrs). Parent of a daughter: 4.8hrs/day (range 1-24hrs)	Additional paid support average of 5.5 hours/day for males and 1.9 hours/day for females
Hartley, Otalora-Fadner & Bussanich (2014)	73 married couples (parents) of children/adolescents with ASD (mean age 12)	Time estimate in online daily diary completed by both parents over 10 consecutive days	Caregiving activities related to the child or adolescent with ASD	Hours/day: Mothers (9.2 ± 2.4); Fathers (7.4 ± 2.5)	Mothers spend significantly more time in childcare than fathers (26% less time). Mothers less involved in paid employment (41% less time) compared to fathers.
Caicedo (2014)	Parents/guardians (n=84) of children (2-21yrs) who are medically complex or technology-dependent	Time diary (minute intervals for one week)	Care burden: **1) Direct care DC** (feeding, bathing, dressing, grooming, toileting, mobility assistance, medication, monitoring, providing treatments) ; **2) Care coordination CC** organising appointments/consultations, ordering equipment/supplies, contacting insurance suppliers, legal consultations; **3) travel to healthcare appointments THC**	**1) DC** hours/week 33 (range 1-168); **2) CC** hours/week 6.6 (range 1-33); **3) THC** 199 mins/month	14.7 hours/week direct care provided by other family members (older siblings, grandparents, other relative)

Sawyer et al. (2011)	Mothers of children (n=) 158) aged 6-17 years with cerebral palsy	Time diary for 24 hour period (5 minute units)	Caring for a child with CP	Mean time spent caring 6.5hrs (SD3.3hrs) per 24hr period. Weekdays (mean 6.0 ± 3.0) vs weekend days (mean 8.3 ± 3.9) Child needing mobility assistance (mean 7.6 ± 3.5) vs no mobility support (mean 5.6 ± 2.9)	More time spent caring if child needed assistance mobilising (p<0.001) and on weekend days (p<0.001). Significant relationship between time spent caring and time pressure and maternal mental health problems.
Şimşek et al. (2014)	Caregivers of chronically disabled children (mean age 6.7 years, n=655)	Time estimate in interview	Daily care time provided to the chronically disabled child	9.96 hours per day (SD 5.18)	
Miller, Nugent & Russell (2015)	Parents/guardians (n=40,242) of child (age<18) with special healthcare needs (CSHCN)	Categories included in the 2009-2010 NS-CSHCN survey	**1) Care coordination CC** (scheduling appointments, keeping healthcare providers up to date, following up services to address child's needs); **2) Providing healthcare HC** (includes monitoring and interventions to manage child's condition)	**Categorical responses 1) CC** 0 - <1hr/week (47.8%); 1-5hrs/wk (43.7%); 6-10hrs/week (4.2%); 11+hrs/wk (4.3%); **2) HC** 0 - <1hr/week (66%); 1-5hrs/wk (20.7%); 6-10hrs/week (5%); 11+hrs/wk (8.3%)	Medical homes associated with lower odds of spending time coordinating care and in healthcare provision

*Description as stated in original article

Abbreviations used in table: ASD = Autism Spectrum Disorder; CP = cerebral palsy; CSHCN = child with special health care needs; FXS = Fragile X syndrome; GT = gastrostomy tube

3.4 References

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Sawyer, M. G., Bittman, M., La Greca, A. M., Crettenden, A. D., Borojevic, N., Raghavendra, P., & Russo, R. A. Y. (2011). Time demands of caring for children with cerebral palsy: what are the implications for maternal mental health? *Developmental Medicine & Child Neurology, 53*(4), 338-343. doi:10.1111/j.1469-8749.2010.03848.x

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Chapter 4 - Parental sleep deprivation

Chapter 4 is a mixed studies systematic review published in *Journal of Family Nursing* in 2015. It focuses on the time spent providing overnight care by parents of children with complex needs and the impact this has on parental sleep length. Quantitative published articles that measure the time spent in care provision overnight, and qualitative studies that include descriptions of sleep quality, length or fatigue are included. Key findings included: 1) the sleep deprivation experienced by parents of children with complex needs is both relentless and draining, impacts on their ability to function and maintain employment, and places a strain on family relationships; 2) the degree of sleep deprivation varies with diagnoses and a key contributing factor appears to be the need for parents to be vigilant at night. These findings provide additional background information in which to situate the primary research studies presented in Chapters 5-8.

4.1 Details of publication

Citation: McCann, D., Bull, R., & Winzenberg, T. (2015). Sleep deprivation in parents caring for children with complex needs at home: A mixed methods systematic review. *Journal of Family Nursing 21*(1):86-118.

Authorship: I conducted the systematic review, undertook the analysis and synthesis of the data and wrote the paper. Professors Bull and Winzenberg supervised the conduct of the systematic review and provided critical review of earlier drafts of the paper.

Journal of Family Nursing has an impact factor of 1.342 and is ranked 15/40 in Family Studies, 24/108 in Nursing (SSCI) and 27/110 in Nursing (SCI) based on the 2014 Journal Citation Reports (Thomson Reuters, 2015). A poster presentation of the systematic review findings was presented at the Australian College of Children and Young People's Nurses (ACCYPN) Conference, Melbourne, 24–27 August 2013 (Appendix 9). The poster was awarded 'Most Outstanding Poster' at the Tasmanian Health Science Research Higher Degree Student Conference in 2013.

4.2 Published paper: Sleep deprivation in parents caring for children with complex needs at home: A mixed methods systematic review

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Chapter 5 - Recoding the Australian Time Use Survey

A detailed understanding of the types of activities that parents are undertaking for or with their children is a key aspect of making visible the invisible work of parents providing care for a child with complex needs. This is only possible if the information regarding the time spent in childcare related activities is obtained at the activity level, rather than in broad categories. An essential aspect of Phase 2 of the research program was therefore to provide a framework that could be used to accurately detail the type of activities parents were performing for or with each of their children, including the child with complex needs.

This chapter begins with an introduction that provides an overview of the types of categorisations and coding systems used in previous time use research with parents of children with complex needs, including limitations in the existing coding systems. The remainder of the chapter details the process of developing additional layers of coding for the Australian Time Use Survey (ATUS) at the specific task level with an emphasis on child related activities required in the care of children with complex needs. It is these additional coding layers that comprise the framework used in the main time use study presented in Chapter 6.

5.1 Introduction

5.1.1 Child care classifications in time use research

Much of the time use research conducted with parents of children with complex needs describes the care of children using broad categories. In the least descriptive versions, all care of children is described under the heading 'childcare' or 'child related activities' (see for example Crowe & Florez, 2006; Crowe, VanLeit, & Berghmans, 2000; Gevir et al., 2006). At best, the care is described using a number of sub categories such as physical care, emotional care, minding children and associated travel (see for example

Cant, 1994; Crettenden, 2008; Edebol-Tysk, 1989). However, no time use study to date has described the care of children with complex needs at the specific task level across the range of areas and activities required to care for a child with complex needs.

In large part this lack of detail can be attributed to the design of the time use studies and the data collection tools used. Many studies use pre-coded diaries, thus capturing only care provided within the categories provided in an effort to reduce the burden on the participants (see for example Crettenden, 2008; Thomas, 2011). Similarly, studies using interviews or survey questions to obtain time use data also restrict participants to broad categories (see for example Barnett & Boyce, 1995; Brust, Leonard, & Sielaff, 1992). With these approaches, there is no ability to explore which child care related tasks occur more frequently. Differentiating the care for the child with complex needs and other children within the family at the specific activity level is also not possible. As a consequence, a substantial gap in the knowledge regarding the type and amount of home care being undertaken and for whom currently exists.

Studies exist that provide useful definitions and descriptions of activities within categories. A number of studies, both qualitative and quantitative, have described the tasks that parents undertake while providing care for their child (see Table 5.1), but no previous time use research has incorporated this level of detail when measuring how parents caring for a child with complex needs spend their time.

Table 5.1: Examples of classifications used to define additional tasks required to meet the needs of children with complex needs

Author/s	Physical care	Advocacy and organisational tasks	Travel related tasks	Monitoring	Therapy or procedure related or should this be technical care	other
Miller, Nugent & Russell (2015)		**Care coordination:** scheduling appointments, keeping healthcare providers up to date, following up services to address child's needs		**Providing healthcare:** includes monitoring and interventions to manage child's condition		
Larson & Miller-Bishoff (2014)	Frequent or extraordinary feeding; constant supervision to ensure self-care needs met	Organising/rearranging families daily schedule to incorporate child's needs		Constant oversight to ensure activity completion; vigilance & monitoring of behaviour to prevent meltdowns	Medical or therapy treatments including attaching/disconnecting technology (e.g. feeding pump)	
Bourke-Taylor et al. (2010)	Assistance with toileting; standing; position changes	Planning, locating and retaining services and supplies; navigating services; completing multiple forms		Close supervision at all times to manage difficult behaviours (tendency to run, aggressive behaviour)	Overnight gastrostomy feeds; care of seizures; pressure care/turning (including overnight);	
Moskowitz et al. (2007)	Hygiene care; bowel & bladder care; transferring; assisting with ambulation	Arranging care; arranging finances (including insurance)	Travel to healthcare appointments; waiting time		Tube care; skin care; diagnostic procedures; crisis care; medication administration	
Plant & Sanders (2007)	Preparing special meals; cleaning up after child; helping/supervising toileting, dressing, bathing, teeth cleaning	Advocating; reading child related information; forms; preparing resources & activities; attending meetings, seminars or workshops	Transporting to appointments; attending appointments	Specific supervision (e.g. at mealtimes) included in physical care	Doing therapy & educational activities; giving medication; providing other medical procedures	
Wilson et al. (2005)	Hygiene needs; bowel/bladder care; tube feeding; transferring; assisting with mobilising	Arranging care; arranging finances/insurance	Travel to healthcare appointments; waiting at appointments		Diagnostic procedures; care of IV/nasogastric /feeding tubes; medications; skin care; tube care; crisis care	Education and training; illness related laundry & housecleaning

Heaton et al. (2005)	Tube feeding;	Managing equipment – ordering supplies, managing stocks; accessing technical support; preparing equipment for use by carers; timing care requirements to fit in with school schedule	Travel to pharmacy for prescriptions	Monitoring using close visual observation and/or use of secondary devices	Care of child on ventilator; assisting child using a device; tube entry/exit care; dialysis; suctioning; oxygen therapy;	Training formal or informal carers
Meehan (2005)		Gathering condition related information; advocating with healthcare professionals & school services; decision making				
Roberts & Lawton (2001)	Skin care; increased hygiene (vomiting, diarrhoea, wounds); frequent changing (incontinence, dribbling); assistance dressing (stiff/floppy limbs); assistance with meals (chewing/swallowing difficulties, behavioural disorders); tube feeds			Overnight supervision of awake child (learning difficulties/behavioural disorders); checking a child having seizures overnight; supervising children lacking danger awareness; constant supervision of child who fits or may choke	Medication administration; care of children dependent on technology; seizure first aid; pain management; care during night time including crisis care, turning, giving medication, tube feeds	Keeping children occupied; stimulation for children with learning difficulties; help with sedentary activities (immobile children); operating medical equipment
Cant (1994)	Assistance with personal care needs; catheterisation; toileting (including bowel evacuations); feeding	Arranging services at school if child not in a special school	Taking to medical and therapy appointments		Delivering early intervention and therapy programs	
Leonard et al. (1992)	Personal care; preparing special meals & cleaning up afterwards	Scheduling medical appointments; talking to healthcare staff	Collect medications; healthcare appointments; waiting time	Being 'on call' to meet contingencies arising due to child's disability	Providing medical care e.g. medications, tube feeds, treat wounds	Monitoring & cleaning medical equipment - ensuring in working order
Turner-Henson et al. (1992)	Special diet				Oral & injectable medications; blood, urine & stool testing;	

*Description as stated in original article

5.1.2 Healthcare related tasks

There is a lack of data concerning the time that parents spend undertaking healthcare related tasks for their child, and the type of tasks requiring the greatest input of time. In the systematic review of time spent in childcare related activities by parents of children with complex needs contained in Chapter 3, healthcare related tasks were separated out from other childcare tasks in only four of the 32 studies, two of which were studies that only measured time in healthcare related activities (McCann et al., 2012). Detail regarding the time spent in healthcare related tasks is provided in two studies not included in the systematic review (Heyman et al., 2004; Miller et al., 2015). A need for more precise and rigorous measurement of specific healthcare related activities and the commensurate time commitment is clearly needed to gain a better understanding of the true time burden associated with 'illness work' (Jowsey et al., 2012, p. 10).

Healthcare related tasks and other activities that need to be undertaken to provide care for a child with complex needs can be broadly classified into seven categories: physical care (with an emphasis on activities of daily living); care coordination or healthcare management; healthcare related travel; treatments and/or therapy; night care; monitoring or supervision; and maintenance of equipment. While the range of tasks and activities varies considerably, there are also key tasks and activities common to diverse populations of children and across a number of studies (see Table 5.1).

The relatively superficial attention paid to healthcare related tasks in time use studies with parents of children with complex needs, with the exception of the studies focused solely on healthcare related time use (Moskowitz et al., 2007; Wilson et al., 2005) is in stark contrast to the descriptions provided in qualitative research. Qualitative studies have described the day to day experiences of parents of children with a range of conditions and needs including children with chronic conditions (Swallow et al., 2011); ASD (Glazzard & Overall, 2012; Hines, Balandin, & Togher, 2014; Safe, Joosten, & Molineux, 2012); diabetes (Sullivan-Bolyai, Knafl, Tamborlane, & Grey, 2004; Whittemore, Jaser, Chao, Jang, & Grey, 2012); Down syndrome or trisomy conditions

(Bruns & Schrey, 2012); seizure disorders (Marr et al., 2015; McDougall, Kerr, & Espie, 2005); cerebral palsy (Glasscock, 2000; Kruijsen-Terpstra et al., 2014); kidney disease (Tong et al., 2008; Tong, Lowe, Sainsbury, & Craig, 2010); and children dependent on technology (Carnevale et al., 2006; Heaton et al., 2005; Kirk et al., 2005). This list is by no means exhaustive. Parents participating in these studies detail the type of care required for their child and describe the difficulties or challenges, including emotional distress, the healthcare related care activities pose for the care givers and other family members.

5.1.3 Tasks relevant to the care of a child with complex needs

Other tasks commonly reported under physical or emotional care categories may also be significantly different for parents caring for a child with functional or intellectual impairment. Many of the time use studies, for example, include feeding, toileting and hygiene as childcare classifications, usually under a 'physical' or 'direct care' category. While these categories are suitable for research undertaken in the general population, broad categories such as these misrepresent the amount and type of care that parents of children with complex needs may need to undertake. Examples include feeding, showering or bathing. Feeding a child with swallowing difficulties can be particularly time consuming, requiring close supervision. For some children, oral feeding may be combined or replaced with feeding via a gastrostomy tube, or occur via a central venous access device in the case of children dependent on parental nutrition.

Showering or bathing a young child is an expected aspect of parenting. While it may be more involved and time consuming when an infant or young child has significant functional limitations, the size of the child makes it possible for one parent to manage the child's personal hygiene needs. As the child grows however, undertaking the same hygiene needs become increasingly difficult and more time consuming. Mechanical assistance such as lifts or slings is needed to assist with mobilising and washing the larger child or adolescent with significant physical disability and functional impairment.

5.2 Recoding the Australian Time Use Survey

Providing further detail about activities in time use studies is not new. Standard codes used to analyse time use diaries in studies with the general population have been elaborated in the past to provide more detail on topics of particular interest (Juster & Stafford, 1991). The Time Use Survey of New Mothers (TUSNM) collected information about activities specific to the childcare activities of that group, including breastfeeding or giving expressed milk or formula, medicating an unwell infant, and teaching eating (Smith & Craig, 2009). But there is a need for further research to explore the specific aspects of care-giving related to the care of a child with complex needs, particularly the tasks that parents find difficult (Plant & Sanders, 2007). Recoding an existing, well established tool ensures the rigour of the data collection and enables a level of analysis currently not achievable.

The Australian Time Use Survey (ATUS) uses best practice methodologies and is widely regarded as an unusually comprehensive and detailed example of a 24 hour time use diary[5] (Craig, 2006; Smith & Craig, 2009). The ATUS is designed for use as a nationally representative survey. Large amounts of information are obtained from participants across wide ranging categories which can be used for cross country comparisons and particularly to describe changes to the time use within a population over time (Gershuny, 2011). Information is captured about the composition of households so that information about specific sub groups within the population can be analysed. However, the data collected is necessarily restricted to the categories used to report and analyse the data.

In order to gain a comprehensive picture of how specific sub groups within the population (such as parents of children with complex needs) are spending their time, analysis of time use needs to occur at the activity level or within more specific sub categories that better reflect the care that is occurring. While the ATUS provides a valid and reliable tool for capturing parental time use data, recoding of the ATUS was required to enable more specific analysis of the data at levels below the broad

[5] A detailed description of the ATUS is provided in Chapter 2

categories used for a population wide survey. A flow chart detailing the development of the recoding framework for the ATUS is presented in Figure 5.1.

5.2.1 Phase 1 – Preliminary development of sub codes

The recoding of activities specific to the care of children with complex needs focused primarily on the broad classifications and codes contained within Section 5: Child Care Activities[6] in the ATUS (Australian Bureau of Statistics, 2008). A preliminary list of childcare related activities that could be considered under these classifications and codes was sourced from relevant studies identified through a preliminary search of the literature and from existing collections (see Table 5.1). The activities were not restricted to particular conditions or diagnoses, but instead were designed to capture the breadth and depth of care provided to children with wide ranging functional abilities and diagnosis related needs.

In the initial stage of the recoding, the broad classifications and codes from Section 5 of the ATUS were entered into an Excel spreadsheet. The preliminary list of childcare related activities sourced from the literature was then entered into the spreadsheet under the relevant sections, creating sub-codes and specific activities within the ATUS classifications and codes. Emphasis was placed on developing sub codes and specific activities to meet the overall aims of the time use study. For example, the ATUS code *511: Physical care of children* was expanded to include sub codes that addressed different aspects of physical care such as sub code *5110: Feeding* and *5112: Toileting* with relevant activities listed under these sub codes. An additional sub code *(513: Healthcare related activity)* was included within the ATUS code *51: Care of children* to specifically address healthcare treatment and therapy provided for/to a child.

5.2.2 Phase 2 – Interviews with allied health professionals

An overview of the study with particular emphasis on the recoding of the ATUS was presented to a professional development meeting of allied health professionals working with children with complex needs in Tasmania. This meeting was attended by a large

[6] A full list of these categories and codes is available in Appendix 8

number of allied health staff with particular expertise in the care of children with chronic conditions and physical and intellectual disability. Importantly, the allied health staff worked closely with families caring for children with complex needs in the home setting and had a strong understanding of the types of therapies, treatments and care activities that parents undertook with their children.

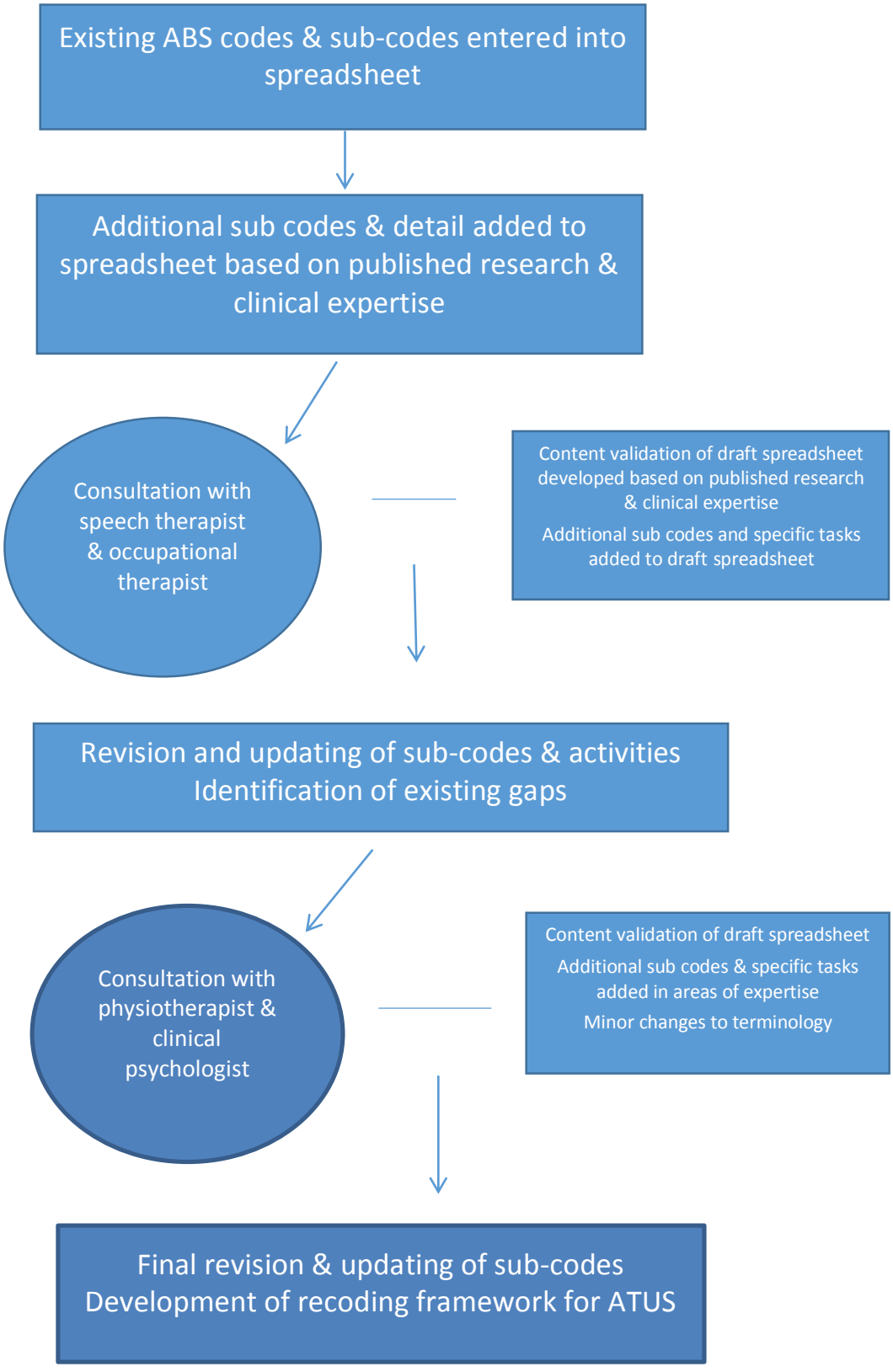
Staff attending the professional development meeting were invited to participate in the recoding of the ATUS in their particular areas of expertise. The staff interested in participating made contact via email. A senior paediatric occupational therapist and paediatric speech therapist responded at this stage, both of whom specialised in the care of children with disabilities and developmental delay and had extensive experience providing care to these children and their families.

Individual face to face interviews were held with the occupational therapist and speech therapist with the aim of validating the additional codes already entered in the draft spreadsheet and expanding on the lists of activities by adding in relevant additional sub codes or specific tasks relevant to the staff member's areas of expertise. Additional sub-codes, specific activities and changes to terminology were suggested by the therapists in their area of expertise and the spreadsheet was updated to reflect these suggestions. Cross disciplinary discussion occurred, with both professionals commenting specifically on the activities within their areas of interest, but also providing additional suggestions for activities in related fields of practice or in broader areas of childcare based on their experience of working with families with a child with complex needs.

Recommendations were received from senior allied health professionals to identify experienced clinicians who could provide further clinical insight to assist in the development of the additional codes. In particular, expertise was sought to address recognised gaps in the development of sub codes in the areas of behaviour management and physical therapy. A clinical psychologist with particular expertise in the diagnosis and management of children with ASD, intellectual disability and sensory processing, and a physiotherapist with specific expertise in the care of children with neurodevelopmental disorders such as cerebral palsy were recommended. Both agreed

to provide expert assistance in the development of the additional sub codes in these areas and to establish content validity. Both were employed in the primary organisation responsible for providing allied health support for children with complex needs and their families in Tasmania and had extensive experience in their areas of expertise. Individual face to face interviews based around the revised spreadsheet were held with both the clinical psychologist and physiotherapist and additional sub-codes, specific tasks and changes to terminology were included or adapted as a result of these interviews.

Figure 5.1: Development of ATUS sub codes relevant to the care of children with complex needs



5.3 Activities included in the recoded version of the ATUS

The original broad categories from the ATUS (numbered from 50 to 59) were used as the high level coding, with the additional sub-codes and activities developed under these broad categories. The detailed activities and sub-codes were numbered using adaptations of the ABS numbering system. In this way, the specific activities and sub-code categories could be easily summarised back into the broad categories used within the ATUS, enabling comparison with population based findings. The final recoding consisted of 21 new sub codes, each with between 2 to 25 specific activities listed within them. The full recoding structure is provided in Appendix 8.

For example, in the original coding system of the ATUS, the physical care of children encompasses any care that meets the physical care needs of a child, including feeding, hygiene needs and toileting. In the recoded version of the ATUS, the broad category *51: Physical care of children* was retained, but divided into the subcategories suggested by the terminology used within the original ATUS coding (toileting, feeding, hygiene/dressing), with the addition of subcategories and specific activities that reflected the type of care that a parent may provide for a child with complex needs. Greater than or less than four years of age was used as the point of differentiation for physical care activities, the age of four generally being an age when children following a normal developmental trajectory are less likely to wear a nappy during the day for example and are gaining skills in performing activities of daily living such as feeding themselves and assisting with dressing and hygiene. An example of the recoding process is provided in Table 5.2.

Table 5.2: Example of specific activity level recoding of the ATUS

Broad ABS category	ABS sub-code with included activities	Examples of revised coding detailing specific activities	
51: Care of children	511: Physical care of children (Carrying, holding, feeding, bathing, dressing, changing babies, putting to sleep. For older children, bathing, cleaning teeth, washing and brushing hair, taking to toilet, getting up, putting to bed, supervising these activities. Also includes minor first aid – putting Band Aids on grazes, removing splinters)	5112: Toileting[1]	51120 Changing nappy (child aged <4yrs) 51121 Changing nappy or pad (child aged >4yrs) 51122Toileting assistance (child aged <4yrs) 51123Toileting assistance (child aged >4yrs) 51124 Bowel massage or evacuation 51125 Bladder massage 51126 Catheterisation 51127 Changing wet bed (child aged <4yrs) 51128 Changing wet bed (child aged >4yrs) 51129 Toileting not otherwise specified
		5114 Assisting with mobility[2]	51141 Transferring child into/out of bed/chair/car 51142 Lifting child aged <4yrs 51143 Lifting child aged >4yrs 51145 Mechanically assisted lift child aged >4yrs 51146 Walking with child requiring assistance 51147 Pushing a child in a wheelchair 51149 Mobility assistance not otherwise specified

[1]Sub-code contained within the ABS example but expanded
[2]New sub-code developed

5.4 Conclusion

This robust recoding process has resulted in a coding framework which provides a high level of detail about the time use associated with childcare related activities, with a particular focus on activities relevant to the care of a child with complex needs. These additional sub codes and activities fit within the structure of the ATUS coding system, enabling a detailed analysis of the type and range of activities undertaken by parents of children with complex needs to be contained within the broader ATUS categories.

The following chapter describes a time use study conducted with mothers of children with complex needs. The recoded ATUS is used in the analysis of this time use study, enabling a detailed analysis of the child related activities undertaken by mothers for or with their child with complex needs, and for or with other children in the family.

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Chapter 6 - Time use of mothers of children with complex needs

We don't stop from the time we get up to the time we go to bed (Mother of a child with ASD)

6.1 Introduction

Although recognised as being the most reliable means of obtaining time use information (Juster, 1985; Niemi, 1993), time use diaries fail to capture the real burden of caregiving and underestimate the time involved (Bittman, Fast, Fisher, & Thomson, 2004). Childcare related activities are classified as primary (the main activity) or secondary (activity occurring simultaneously or in addition to main activity) (Craig, Mullan, & Blaxland, 2010). Primary childcare activities are the most amenable to cross country comparisons and the measurement of trends over time, but significantly underestimate the total amount of childcare that is occurring and misrepresent the care process as a whole (Mullan and Craig 2009). Previous time use research with parents of children with complex needs frequently focus on (and may only collect) time spent in primary child care activities and this is perhaps a key factor in why many of these studies fail to show a significant difference between parents of children with complex needs and comparison groups of parents with children who are typically developing (McCann et al., 2012).

The unlikely (although not statistically significant) finding from an Australian study that parents of children with disabilities spent less time caring than parents of children in the general population provides an example. In this study, the time spent caring by parents of children with disabilities was compared to parents in the national 1997 ATUS (Crettenden, 2008). The discrepancy (a total of 15 minutes more in childcare per day for females in the general population compared to the mothers of children with disabilities) may be largely explained by the fact that the classification of time use for the parents of children with complex needs was time spent in primary childcare, compared to time spent caring (as a primary or secondary activity) for the parents in the ATUS (Crettenden, 2008). The large amounts of time that parents in the ATUS sample spent 'minding' their child counteracts the fact that these parents spent much less time in

'active' childcare compared to the parents of children with complex needs (Crettenden, 2008). Compounding this is the fact that the ATUS classifies childcare activities as priority activities in order to ensure these activities are captured as part of unpaid work, in most cases coding them as primary activities even if the activity was recorded on the diary as a secondary activity (Australian Bureau of Statistics, 2008).

Differentiation between primary and secondary activities is a key consideration when measuring time spent in caregiving activities, with childcare and other caring activities more likely to be recorded as secondary activities rather than primary (Kenyon, 2010). Floro and Miles (2003) reported an average of 157 and 75 minutes spent in primary childcare by women and men respectively, substantially less than the 478 and 302 minutes recorded for secondary childcare. In later research, the total weekly time spent in childcare activities by Australian parents was four times greater when primary and secondary childcare was considered together rather than as primary time alone (13hrs per week vs 3.6 hours per week), although even this underestimates the amount of time that would be reported if parents included their total responsibility time (Ironmonger, 2004). Clearly then, accurately recording and measuring all the time that parents are spending in childcare is crucial to obtaining a clear picture of what is occurring each day.

An inherent difficulty in using time use diaries to measure time spent in childcare is the focus on activities only, rather than the associated constraints or responsibilities, and this has significant implications for the way that childcare and the care of people with a disability or the frail elderly is measured and reported (Bittman, Fast, et al., 2004; Budig & Folbre, 2004). Monitoring and supervision are an essential part of responsive and responsible care, but fail to be acknowledged unless childcare that is occurring as a background activity is captured (Craig & Bittman, 2008). This background childcare activity is frequently referred to as passive childcare, 'time that is constricted by the need to care for a child', either by being in proximity to them or responsible for them (Jones, 2008 p.3).

Different methods are used to measure passive childcare in national time use surveys. The New Zealand Time Use Survey uses the responsibility method, specifically asking

respondents if they were responsible for the care of a child in an interview following completion of a 48 hour diary, while the ATUS relies on respondents to record passive childcare, primarily as a secondary activity (Jones, 2008). The New Zealand Time Use Survey includes passive care of children when the adult and child are sleeping, but time that the respondent is sleeping is excluded from this category in the American Time Use Survey (Jones, 2008). Few national studies explore the intensity of caregiving, even though time spent being available or on call for the disabled may be as relevant as the time that caregivers are devoting to activities with them (Smeeding & Marchand, 2004). A case can be made for always classifying the care of young children or the frail or disabled elderly as an overriding primary activity (Ironmonger, 2004).

More than 30 studies have measured the time spent providing care by parents and carers of children with complex needs (McCann et al., 2012). These studies vary considerably in the way the time use is measured and the level and amount of detail regarding parental care activities that is obtained. While the research provides information to guide policy decision making, the data is predominantly general, with very limited focus on specific childcare activities and the time allocated to them by parents. Time spent on healthcare related activities is poorly measured (McCann et al., 2012), despite this often being a key focus for parents of children with complex needs. The overlap between typical child care and atypical child care also means that added health care work may often remain largely hidden (Leiter, 2004).

In addition to activities that may be largely hidden, many of the mundane and seemingly routine activities in daily life, such as eating, dressing, toileting and moving around, are altered, renegotiated and become more complex when providing assistance to a person with long-term care needs (Yantzi et al., 2007). The presence of family members with a disability in a household also affects the amount of general housework and the way in which it is distributed amongst the family members (Miller & Bowd, 2012). Extra household work specifically involved with having a child with an intellectual disability or ASD may include more cleaning and washing and the need for repairs to wallpaper, toys and furniture due to destruction by the child (Olsson & Hwang, 2003).

Comprehensive measures of time use do exist. For example, the ATUS has been described as the 'Mercedes of time-use surveys' (National Research Council, 2000 p. 30). There are five columns, allowing for data to be collected about primary and secondary activities, who the activity is performed for/with, who the person is with at the time and their location (Australian Bureau of Statistics, 2008). However, even this highly regarded time use diary has significant limitations when used with parents of children with complex needs. The broad categories in the ATUS include meal preparation, domestic and household work, transport, healthcare, communication and mobility, all of which may be involved in care provision, but little or no detail is provided regarding what is involved in these activities and the time spent in each (Jowsey et al., 2012). Health is identified as an activity on which time is spent, but there is no detail obtained regarding specific activities and how frequently they are occurring (Jowsey et al., 2012). Providing healthcare to a child is even less visible, any healthcare provided by a parent or carer for a child included in a classification that covers all physical care of a child (Australian Bureau of Statistics, 2008). While the ATUS captures total parental care time, it does not differentiate between care spent with each individual child (Craig, 2006).

Gaps exist in the information available regarding the time use of parents of children with complex needs despite a large body of research in this area. This time use study therefore aimed to describe the time use of parents of children with complex needs using additional coding options developed for the ATUS[7] to enable detailed analysis and description of the types of childcare activities parents were undertaking, with a focus on healthcare related tasks and tasks specifically undertaken to meet the needs of child with complex needs. A secondary aim was to describe how parents divide their time in childcare activities between their child with complex needs and other children in the family.

[7] These coding options are described in detail in Chapter 5

The study addresses three main questions:

1) How much time do parents of children with complex needs spend in childcare related activities in a 24 hour period?

2) What types of childcare related activities are undertaken by parents of children with complex needs?

3) How does the time parents spend in childcare related activities for the child with complex needs compare to the type of activities and amount of time spent in childcare related activities for other children in the family?

6.2 Methods

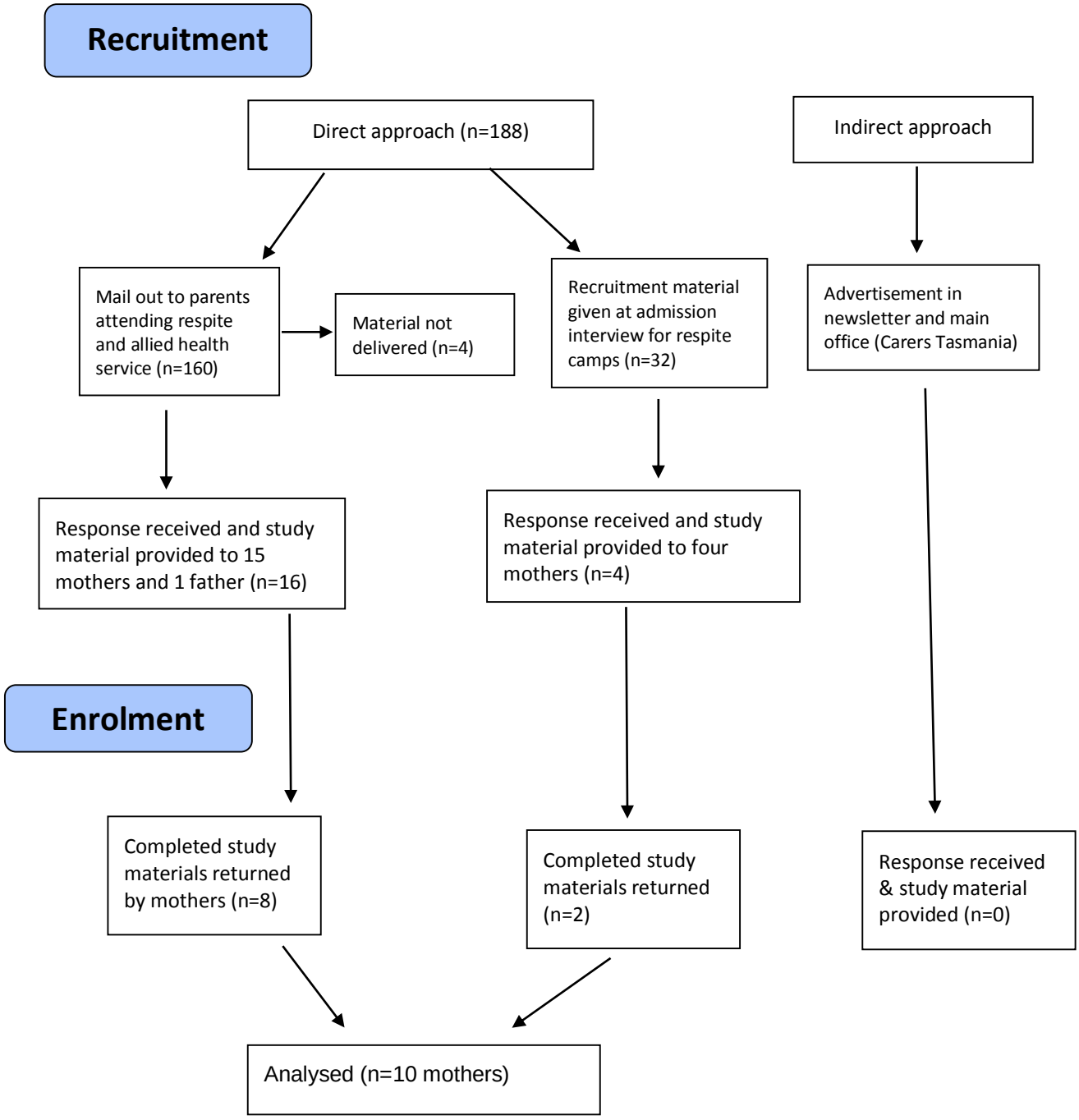
6.2.1 Design

This was a cross sectional time use study using the Australian Time Use Survey (Australian Bureau of Statistics, 2008).

6.2.2 Sample

Parents were recruited by direct approach through existing services and via advertising through Carers Tasmania (see Figure 6.1). Direct approaches were made through: 1) a service provider; and 2) a respite camp for children with complex needs. Parents were initially informed about the study via an introductory letter, sent with a consent to contact form and self-addressed envelope. Parents who returned the consent to contact form were then contacted by phone and provided with additional information. A total of 188 parents were provided with the initial introductory letter via direct approach (see Figure 6.1). Information was also distributed indirectly via the newsletter of Carer Tasmania and displayed on the notice board in the Carers Tasmania main office.

Figure 6.1: Flowchart of time use study recruitment and enrolment



6.2.2.1 Recruitment via service provider

One hundred and sixty parents of children who attended a local organisation providing respite care and a range of allied health services to children with disabilities and special healthcare needs were initially contacted by post by a staff member working within the organisation. This organisation can also be accessed by parents who self refer their child for one off or small scale services, for example, handwriting assistance or a developmental assessment. To ensure that the letter was sent only to families caring for a child with complex needs, allied health professionals within the organisation screened the potential list of participants. Four letters were returned to sender, leaving a total of 156.

6.2.2.2 Recruitment via respite camp

Thirty-two parents were given the recruitment materials during the admission interview for a child attending a Christmas Camp at a local high school. This camp is part of the Sony Foundation Children's Holiday Camp Program that supports young Australian's with disabilities and their families (Launceston Church Grammar School, 2015). The camp aims to provide an enjoyable weekend of activities for a child with complex needs while providing respite to parents and daily care-givers (Launceston Church Grammar School, 2015). Potential camp attendees are suggested by teachers at the child's school following discussion with the child's parents and parents can also apply directly. The envelopes were handed to the parents by the nurses doing the interview admissions for the December 2010 and 2011 camps.

6.2.3 Pre data collection interview

Study packs were provided to 20 parents who indicated an interest in being involved in the study, one father and 19 mothers (see Figure 6.1). It is essential that written study instructions, the data being collected and advice on diary completion is clearly understood by study participants (Nicholl, 2010). To facilitate this, preliminary interviews were arranged with all potential participants to explain the study and particularly to ensure that the parents understood how to complete the time use diary. Face to face interviews were held with 15 parents. At this interview the parents were

provided with a study pack containing the time use diary, questionnaires, and consent form. A phone interview was held with two parents at their request and the study pack posted out. Three parents were not at home at the time of the pre-arranged interview. The study pack was left and follow up was attempted by phone without success.

6.2.4 Follow up phone calls

The parents were asked to complete the diaries and questionnaires and return them in the envelope provided. One follow up phone call to check whether the parent was still interested in being in the project and to answer any questions they may have was undertaken with all participants who did not return the study pack. A second phone call was attempted if the first call did not result in a conversation with the parent.

6.2.4.1 Feedback regarding non participation

The follow up phone calls provided an opportunity to gain feedback from parents about the study, including reasons why they were unable to participate or chose not to. One mother of a child with behavioural difficulties and intellectual disability stated that she had tried doing the diary, but every time she went to write in it her son interrupted her. It had made her realise how often he interrupted her doing tasks during the day. Another mother contacted via the follow-up phone call explained that she was not able to commit to the research due to the high needs of her child at this time. The mother appreciated that this was the point of the study, but explained that they were commencing a new treatment for her daughter which would involve intensive therapy 5 days a week (3 month program) that the parents would do at home and that her daughter had also had complications from surgery performed a couple of months ago – the mother stated that there had been 'a lot going on'.

One mother posted back the "Consent to contact form' with the following explanation (permission was received from the mother to reproduce her words here):

> *Thank you for your study in this area – I am sure that your statistics will help others understand the overwhelming task of carers. I am sorry to decline your offer but I am a single parent who works full-time in a demanding job. A child with a disability on top of this is also bedlam as you can imagine …. As it is I only get 4-5 hours of sleep per night so I can't really squeeze this in. Thank you once again.*

6.2.5 Data collection tools

6.2.5.1 Demographic questionnaire

A demographic questionnaire was used to collect background information related to the child and family, and healthcare usage by the child with complex needs over the preceding year. No questionnaire was available that covered all the required aspects, so a questionnaire was developed specifically for the study (Appendix 3). The questionnaire was reviewed by two mothers of children with complex needs not involved in the study (a mother of a child with intellectual and physical disabilities and a mother of a child with ASD) to establish face and content validity. A rewording of the question regarding the child's diagnosis to make the purpose of the question clearer was recommended by one of the mothers. No other changes were required.

6.2.5.2 Australian Time Use Survey (ATUS)

An adapted version of the ATUS was used to collect the 24 hour time use information. The diary is set out in columns that collect information about the respondents' primary activity (what they were doing); who they were doing the activity for; whether they were doing anything else at the same time (secondary activity); their location; and who they were with (Australian Bureau of Statistics, 2008b). Information is obtained in free form, the participants recording their activities in 5 minute blocks over a 24 hour period.

The official version of the ATUS has a 5th column headed '*Who was with you at home, or with you away from home?*' While there is value in gaining information regarding who is present within and outside the home, a key limitation in the findings of the ATUS conducted in the general population is the inability to isolate the time spent caring for each individual child in families with more than one child (Bittman, Craig, & Folbre, 2004). There is limited understanding of how parents of children with complex needs meet the care needs of all of their children (Koch & Mayes, 2012). Minor adaptation to the ATUS was therefore made to facilitate collecting this information. The fifth column was removed and participants were instead asked to indicate who they were undertaking an activity for or with for both primary (what they were doing) and secondary (what else they were doing at the same time) activities. In particular, participants were asked to assign a number to each of their children, identifying the age of the child and whether or not the child had special care needs. This numbering system was then used to indicate which child was involved when undertaking a primary or secondary activity for or with a child. All other aspects of the original version of the ATUS were retained (see Appendix 4).

Participants were asked to complete the diaries over two 24 hour periods, a week day and a weekend day. A single diary day is the emerging modern standard for national time use surveys (Gershuny, 2011) and was the approach used in a study using the ATUS in a population of parents of children with complex needs (Sawyer et al., 2010). A two day approach was chosen for this study however, to get a clearer picture of what was happening for the parent completing the diary and to enable comparisons between care on weekdays and weekends. Collecting diaries for a weekday and a weekend day is a common method used when collecting diaries for more than one day (National Research Council, 2000).

6.2.5.3 Time Crunch Scale

The Time Crunch Scale (Robinson & Godbey, 1997) was used to measure the time pressure experienced by the mothers (Appendix 7). The Time Crunch Scale is a 10 item scale developed to assess time pressure as one aspect of gaining a better understanding of how respondents perceive time in a national survey of time use in the USA (Robinson

& Godbey, 1997). A total score for the Time Crunch Scale is calculated from the number of items agreed with by respondents (range = 0 to 10), with a higher score indicating the person is experiencing greater time pressure (Sawyer et al., 2010). The Time Crunch Scale has previously been used in time use studies conducted with parents of children with ASD (Sawyer et al., 2010) and parents of children with developmental disabilities including Down syndrome, autism and global developmental delay (Crettenden, 2008). No information is available regarding the psychometric properties of the Time Crunch Scale.

6.2.5.4 Amount of Assistance Questionnaire

The Amount of Assistance Questionnaire AAQ (Msall et al., 2004) was used to assess the amount of assistance with daily activities required by each child (Appendix 6). Measuring the functional limitations of a child provides an opportunity to assess the effect of an individual child's limitations on the way a parent allocates their time, information that cannot be obtained through the use of a diagnostic label alone (Brandon, 2007). The AAQ is a discipline-free measure of the level of assistance needed by a child compared to their peers that is divided into domains including developmental skills and specialised therapies and with a final section containing seven questions including the amount of assistance required by the child for eating, dressing, toileting and locomotion (Msall & Tremont, 1999; Ottenbacher et al., 2000). A short version of the AAQ containing this final section (Msall et al., 2004) was obtained from the first author and used for this study.

Four questions in the final section of the AAQ ask the parent '*How much assistance does your child need in completing the following activities?*' (eating, dressing, toileting and locomotion) rated on a five point scale where 1=none (0% assistance) and 5=total assistance (100%). A rating for the amount of assistance required by a child is obtained by summing the scores obtained from these four questions (Ottenbacher et al., 2000). Intraclass correlation values ranging from 0.82 – 0.97 were obtained in test-retest reliability testing of the AAQ (Ottenbacher et al., 2000). There was a statistically significant (rho = 0.57; $p<0.005$) correlation between the AAQ score obtained from the four questions in the final section of the AAQ and established levels of severity in 205

children with developmental disabilities in validity testing of the AAQ (Ottenbacher et al., 2000).

6.2.5.5 Child's Challenging Behaviour Scale

Challenging behaviours exhibited by the child with complex needs was assessed using the *Child's Challenging Behaviours Scale (CCBS)* version 1 (Bourke-Taylor, Law, et al., 2010) (Appendix 5). The CCBS is a short, psychometrically sound instrument that measures challenging behaviours exhibited by a child with a disability from the perspective of their mother (Bourke-Taylor et al., 2010; Bourke-Taylor, Law, & Howie, 2010b). Eleven items are included in the scale and respondents rate their level of agreement with each statement using a 5 point Likert scale, where 1=strongly agree and 5=strongly disagree (Bourke-Taylor et al., 2010b).

A total score is obtained for the CCBS by reversing items 3 and 6 and then summing the scores, with possible scores ranging from 11 – 55 and higher scores indicating more challenging behaviours (Bourke-Taylor et al., 2010b). Initial testing of the CCBS demonstrated high internal consistency (Cronbach's alpha 0.89) and the tool was deemed to be normally distributed based on test of normality with mean score 34.4 (SD 9.3) and range 11 – 54 (Bourke-Taylor et al., 2010b; Bourke-Taylor, Law, et al., 2010). Statistically significantly higher scores were obtained in independent samples *t*-tests for children with ASD compared to children without (37.2 vs 29.7; $p<0.001$), demonstrating the ability of the tool to differentiate groups of children with more challenging behaviours (Bourke-Taylor, Law, et al., 2010).

A later version of the CCBS was published in 2013 (Bourke-Taylor, Law, & Howie, 2013) after Rasch analysis revealed problems with the 5-point response format (specifically the *neither agree nor disagree* mid-point of the scale) and the redundancy of two items (Bourke-Taylor, Pallant, & Law, 2014). This version was not available at the time of data collection so results for the CCBS are presented based on the reporting format for version 1.

6.2.5.6 Photo-interviews with key informants

Photo-interviews using a self-directed photography approach were held with two mothers, a mother of a child with ASD and a mother of a child with Rett syndrome and comorbidities. These mothers acted as key informants, contributing their knowledge and understanding of what is involved in caring for a child with complex needs on a daily basis. This knowledge and understanding provided context for the time use findings and assisted with interpreting what was happening and why (Patton, 2002).

The mothers took photographs that represented their daily activities and home life. These photographs formed the basis for a semi structured face to face interview held at the mother's home. The interviews were taped and transcribed. Descriptive analysis of the transcripts was undertaken with reference to the photograph when appropriate/relevant. These descriptions were then used to provide context for the time use findings, or in some cases to provide an additional level of detail that assisted in the analysis of the time use data.

6.2.6 Data analysis

The 20 diaries from 10 participants represented a small sample of very diverse cases which precluded detailed statistical analysis. The data obtained from the diaries was therefore treated like a case series rather than using inferential statistics.

Descriptive statistics, primarily frequencies, were used to summarise the primary and secondary activities for each 24 hour period. This occurred at the specific (detailed) code level and for combinations of activities. Summary statistics (medians and ranges) were used to describe time spent in main categories of activities such as childcare related activities or personal care and leisure activities across the sample. Relevant time cut points were used where appropriate to summarise data across the sample and to enable within sample comparisons.

6.2.6.1 Coding of the time use diaries

All participants were assigned a study code (SC) number. Coding of the time use diaries was undertaken in the first instance using the hard copy versions of the completed diaries returned by the participants. The relevant code was written against the activity entered in the first and second column for each of the 5 minute time blocks. ABS codes (Australian Bureau of Statistics, 2008) were used for all non-childcare related activities. Specific activity level codes were assigned to all childcare related activities based on the recoding of the ATUS described in Chapter 5.

There were two 24-hour diaries per mother, with each diary able to contain a maximum of 288 primary (first column) and 288 secondary (second column) activities. An excel spreadsheet was created to enable comprehensive analysis of the primary and secondary activities occurring every five minutes over a 24 hour period. The relevant codes for the primary and secondary activities (if applicable) occurring within each five minute time block and the person for whom the primary and secondary activity was performed for/with (if known) was entered (see example Figure 6.2). This resulted in 288 sections containing up to 4 lines of data per diary day for each participant. This data was then transferred into a SPSS 20 database to enable further analysis.

Figure 6.2: Example of excel spreadsheet detailing coded primary and secondary activities and person/s for whom the task is performed in 5 minute time blocks

	0830	**0835**	**0840**	**0845**	**0850**	**0855**	**0900**
P013[a]	5822	5820	5820	5820	5822	51147	981
Person[b]	1+2+3+4	1+2+3	1+2+3	1+2+3	1+2+3	1	9
S013[c]	5330	943	943	943	5714	5722	5330
Person	2+3+4	9	9	9	1	1	4

[a]represents study code 13, primary activity; [b]represents study code 13, secondary activity; [c]person that the task is being done for or with (where 1-4 = the numbering system allocated to the children in the family and 9=self)

Descriptive statistics, primarily frequencies, were used to summarise the primary and secondary activities at the specific (detailed) code level. Minor categories were then

created to further summarise the activities within categories that fit under the broad framework of the ABS classification system (see examples Table 6.1).

Coding the childcare related activities at the specific activity level using the recoded version of the ATUS enabled a calculation of the amount of time mothers were spending in childcare related activities that could reasonably be classified as additional activities required to meet the needs of the child with complex needs. These calculations included healthcare related activities, but also incorporated physical and other childcare activities that were required to meet the child's complex needs including for example a full oral feed for an older child, showering/bathing and dressing an older child, positioning and assistance with mobility. These minor categories were then further summarised into the broad ABS classifications (see examples Table 6.1). The broad classification of all of the non-childcare related activities corresponded with the ABS categories with the exception of activities related to maternal sleep, which were not included within the broad *1 Personal care activities* classification. Maternal sleep was given separate codes (sleeping; co-sleeping; awake at night) to enable more detailed analysis of this data. The reported sleep times represent the time the mothers spent asleep in five minute time blocks across two time periods per 24 hours (from 12am until time awake in the morning and then from time of going to sleep that night until 12am the following morning) rather than one full night.

Childcare related activities were classified within the structure of the ABS categories, but were not always summarised into the highest level classification. For example, the broad ABS classification for childcare is *5 Child care activities* which contains the classification *51 Care of children* encompassing all physical and emotional care of children. This classification was too broad for the purposes of this study so the classification levels below the broad classification (*511 Physical care of children* and *512 Emotional care of children*) were used as the broad categories.

Table 6.1: Examples of classification of specific activities into minor and broad categories

Examples of specific activities	Minor category	Broad category
151 Eating meal* 152 Eating snack* 153 Drinking non-alcoholic beverage*	15 Eating/drinking	*1 Personal care self* (also includes personal hygiene, personal healthcare)
51102 Assisted/supervised oral feed (child <4yrs) 51103 Assisted/supervised oral feed (child >4yrs) 51104 Full oral feed (child<4yrs) 51105 Full oral feed (child>4yrs) 51106 PEG feed	5110 Feeding	*511 Physical care of child* (also includes toileting, dressing/hygiene)
5330 Talking with child – verbal interaction 5331 Talking with child using Assisted Communication Device 5332 Communicating with child who uses non-verbal communication 5333 Answering questions	533 Talking with child	*53 Engaging with child* (also includes reading, playing, helping, reprimanding)

*ABS codes

6.2.6.2 Classification of activity combinations

Combinations of activities occurring simultaneously (primary and secondary activities undertaken in the same five minute time block) were explored and summarised using the data entered into the excel spreadsheet (see figure 6.2). Each five minute block of time per diary day per participant was descriptively analysed to establish:

- how frequently combinations of activities (for example, a primary domestic activity coupled with a secondary childcare activity) were occurring across the 24 hour period

- the number of primary and secondary activities occurring for/with the child with complex needs and/or other children

- the number and type of activities occurring in isolation and if possible, who they were occurring for/with

- the time of day (daytime, evening, night) particular activities were more or less likely to occur

The most commonly occurring combinations of activities covered three main areas (six combinations). These were:

- Primary domestic activity and secondary childcare activity

- Primary childcare activity and secondary domestic activity

- Primary domestic activity and secondary maternal personal care/leisure activity

- Primary maternal personal care/leisure activity and secondary domestic activity

- Primary maternal personal care/leisure activity and secondary childcare activity

- Primary childcare activity and secondary maternal personal care/leisure activity

Coding of activities as sole activities focused on five classifications that were of particular interest with regards to the care of children and maternal time use:

- Childcare activity undertaken for/with child with complex needs
- Childcare activity undertaken for/with another child
- Childcare activity undertaken for/with more than one child (+/- child with complex needs)
- Maternal personal care/leisure activity occurring as a sole activity
- Childcare activity occurring as a sole activity

Descriptive statistics were used to summarise the types of activity combinations occurring for the individual diary days and how frequently these combinations were occurring. Similar analysis was undertaken for the sole activities, with an emphasis on who the activity was being performed for/with where possible.

6.2.6.3 Classification of activities as primary or secondary

The diaries were all interpreted and coded according to the way the information was presented by the mothers. An activity was classified as a primary activity if it was written in the first column (*What were you doing?*) and as a secondary activity if it was written in the third column (*What else were you doing at the same time?*). This was strictly adhered to even though some activities (particularly childcare) recorded as secondary activities were more indicative of a primary activity. For example, in the extracts below (Figure 6.3), domestic activity was classified as the primary activity and childcare as the secondary activity, despite the childcare requiring the active involvement of the mother.

Figure 6.3: Examples of diary excerpts where active childcare is recorded as secondary activity

Example 1

Time	What were you doing?	Who did you do this for?	What else were you doing at the same time?*
1905	Cleaning	Self	Attending to
1910			children's
1915			showers,
1920			dressing them up
1925			

*as written by the mother

Example 2

Time	What were you doing?	Who did you do this for?[a]	What else were you doing at the same time?
0730	Fed children breakfast	Child 1&2	Read newspaper
0735			
0740			Gave child 2 medication
0745			Said goodbye to husband
0750	Cleaned up kitchen	Self	Unstrapped children
0755			Placed child 1 in special chair
0800			Comforted sick child 2
0805			Child care
0810			

[a]child numbering system as allocated by mother when completing the diary. Child 1 is child with complex needs

Alteration was made to the mother's depiction of what was a primary and secondary activity on only one occasion. In this instance, the mother had entered a number of childcare related activities in the first column with gaps in between (see Figure 6.4). Although an assumption could be made that the mother was also closely observing her child during the periods between suctioning, no child related activities could be coded for these time periods because no additional activities had been recorded. In the secondary column, the mother had written two activities occurring simultaneously (watching TV/talking to husband) and then drawn an arrow down the page, indicating these were continuous activities. The five minute time block sections where child related activities were written in the first column were coded as a child related primary activity (eg. 5138 suctioning a child) with *watching TV* and *talking to husband* coded equally as secondary activities. For the time blocks where no information was entered in the primary column, *watching TV* was coded as the primary activity and *talking to husband* was coded as the secondary activity.

Figure 6.4: Diary excerpt where secondary activity reclassified as primary activity

Time	**What were you doing?**	**Who did you do this for?** [a]	**What else were you doing at the same time?***
1945	Bladder massage	Child 2	Watched TV/ talked to husband
1950	Changed nappy		
1955	Suctioned child		
2000			
2005			
2010	Suctioned child		
2015			
2020			
2025			
2030	Said goodnight to child	Child 1	

[a]child numbering system as allocated by mother when completing the diary. Child 2 is child with complex needs

6.2.6.4 Dealing with missing data

Gaps existed in some of the diaries between documented activities. In the more detailed diaries, mothers filled in the majority of the five minute time blocks, frequently completing activities for both the primary and secondary columns. Arrows were also used to indicate how long an activity had taken for activities occurring over a number of time blocks.

In some instances, less information was provided regarding the types of activities that were occurring and arrows were not used to indicate continuing tasks, resulting in a number of time blocks being left blank. Where logical and justifiable, assumptions were made regarding the activity that may be occurring in the missing space. For example, where a mother had entered 'Preparing medication for child 1' followed by an empty space and then 'Giving medication to child 1', medication preparation was coded for 2x5 minute time blocks and administering medication for 1x5 minute block. In another example, a mother had written 'driving home' in one time block, left the next three time blocks blank with no arrow and then written 'getting children out of car'. Driving was therefore coded for all spaces between driving home and 'getting children out of car' (20 minutes in total). If filling in the blank time periods required an estimate that could not be clearly justified, the space was left blank and this appeared as missing data.

6.2.6.5 Photo interviews

Stories and descriptions provided by the mothers are used throughout the results section to provide contextual information that expands on the time use findings.

6.2.7 Ethical approval

Ethical approval for the time use study was obtained from the Tasmanian Social Sciences Human Research Ethics Committee, application number H0011241 (Appendix 1).

6.3 Results

Completed diaries and questionnaires were received from 10 mothers, a 50% response rate from parents who received a study pack and 5% response rate from parents who received the initial study information (see Figure 6.1). Two completed diaries and all study questionnaires were received from all mothers with the exception of two mothers who did not do the CCBS because their child was too young (recommended for children aged 5 years and older). Two mothers (SC5 & 11) completed their diaries on weekdays only, the remainder completed a diary on both a weekday and a weekend day.

6.3.1 Demographic characteristics

Characteristics of the child with complex needs and family is presented in Table 6.2. The ages of the child with complex needs ranged from 18mths to 13yrs and all of the children had at least one sibling. Despite the children with complex needs having a range of diagnoses, some conditions or features occurred in a number of children as either a primary or coexisting condition, including four children with a diagnosis of ASD, five children with epilepsy or seizures, and five children with developmental delay (Table 6.2). Five children had been admitted to hospital in the previous year and two children had each had four visits to the emergency department of the local hospital. Work days had been missed in the previous year to care for the child with complex needs by one or both parents in six families, the number of days ranging from 3 to 38 (see Table 6.2).

All of the children required assistance with completing activities of daily living as measured by their scores on the *Amount of Assistance Questionnaire*. Half of the children scored 17 or above, indicating a very high assistance requirement, including three children who required total assistance with all activities (see Table 6.2). Eight children had a behavioural score based on the *Child's Challenging Behaviour Scale*, with scores ranging from 18 to 38 (see Table 6.2), the higher scores indicating that the child exhibits more challenging behaviours (Bourke-Taylor et al., 2010b). Scores from the Time Crunch Scale ranged from 3 to 9 (see Table 6.2). This score was calculated only out of nine items for five mothers (participants 4, 5, 9, 11, 13) because item 7: *When I'm working long hours, I often feel guilty that I'm not at home* was not applicable to them.

Table 6.2: Characteristics of child with complex needs and their family

Study code no.	Age of child	Diagnosis of child with complex needs	AAQ score[a]	CCB score[b]	TCS score[c]	ED visits[d]	Hospital admission[e]	Total days work missed[f]	Other children <4yrs	Other children >4yrs
1	7	Dyspraxia, DD, epilepsy, Autism Spectrum Disorder	12	38	3	0	0	10	N/A	1
4	13	Uncontrolled epilepsy, DD, low muscle tone	19	30	8	0	1	0	N/A	1
5	7	Autism Spectrum Disorder	11	33	9	0	0	0	N/A	1
8	12	Autism Spectrum Disorder	14	37	7	0	1	3	1	1
9	18mth	Cerebral palsy, developmental delay	20	N/A	2	0	1	0	1	N/A
11	9	Rett syndrome, epilepsy, osteoporosis	20	24	2	4	3	38	1	1
13	9	Hydrocephaly, cerebral palsy, seizures, bronchiectasis, osteoporosis	20	25	4	4	3	3	1	2
19	11	Global developmental delay	14	18	3	0	0	3	1	N/A
20	4	Angelman syndrome, severe developmental delay, epilepsy	17	N/A	7	0	0	4	N/A	1
24	4	Autism Spectrum Disorder (high functioning)	10	23	4	0	0	0	1	N/A

[a]Amount of Assistance Questionnaire score; [b]Child's Challenging Behaviour score; [c]Time Crunch Scale score

[d]Number of visits to Emergency Department for child with complex needs in previous year

[e]Number of times child with complex needs admitted to hospital in previous year

[f]Total number of work days missed in previous year while caring for child with complex needs (one or both parents)

6.3.2 Overview of maternal time use

A broad overview of maternal time use excluding childcare is presented in Table 6.3. The combinations of activities that mothers engaged in simultaneously is presented in Table 6.4. A summary of key aspects of maternal time use, including time spent in simultaneous activities is presented in Table 6.5. The information presented in these tables is expanded on in the text below.

6.3.2.1 Work

Four mothers worked outside the home on at least one of the diary days, the time spent at work ranging from 5½ to 7 hours. One mother (SC9) worked for 2 hours at home while caring for two infants.

6.3.2.2 Recreation and personal care time

The percentage of the 24 hour period spent in recreation as a primary activity ranged from 0 to 21%. Seven mothers (70%) spent no more than 2.4hours (10% of time) in primary recreation activities across both their diary days. Two mothers reported doing exercise, a walk with their child (SC20) and a gym class (SC13).

Primary and secondary personal care and recreation activities were frequently combined with either domestic/household activities or childcare (Table 6.4). In sixteen diary days (80%), the mothers spent 10% or less of their time in either personal care or recreation activities as sole activities (not combined with another activity). This reduced to 5% or less of the allocated time in 12 diary days if only personal and recreation activities as sole activities prior to 9pm were considered (Table 6.4 and example Box 1).

Box 1*: I was just amazed at what I did in a day – and what I didn't do for myself. It was all family driven…Everything in that diary apart from getting myself ready for work and going to work for those five hours…apart from making a cup of tea and going to bed to read a book and trying to talk to your husband at the same time while he's reading a paper…and I thought this is the only time apart from when you go to bed and go to sleep that you had time to yourself (SC5)*

6.3.2.3 Domestic and/or household related activities

Domestic or household related activities were consistently recorded as primary rather than secondary activities and accounted for considerable amounts of the mothers' time (Table 6.3). In more than half the diary days (60%), four or more hours were spent in domestic or household activities (maximum of 10.8 hours) (Table 6.3). Primary domestic/household activities were frequently combined with childcare as a secondary activity (Table 6.4). The percentage of time spent in primary domestic activity that also included a secondary childcare activity ranged from 9-91% (median 47%). In nine diaries (seven mothers), 50% or more of the primary domestic activity time occurred simultaneously with a secondary childcare activity, including seven diaries (four mothers) where this combination occurred in 75% or more of the primary domestic activity time. The combination of household related activity and childcare increased the time required to undertake certain activities for one mother of a child with ASD (Box 2).

> **Box 2:** *Going to the supermarket would probably take twice the amount of time…because you have to be forever vigilant as to what he is doing. And if you don't go a certain way down an aisle he'll tell you…'You're going the wrong way' at the top of his voice and make you turn around. Or if I decide I don't need anything up that aisle he'll say 'we're going down this one' at the top of his voice…so everything takes that bit longer (SC5)*

6.3.2.4 Sleep

The median time spent asleep was 7 hours (minimum 5.1, maximum 10.3) (see Table 6.3 and Table 6.5). Four mothers (five diaries) reported less than 6 hours sleep within the 24 hour period. At least one interruption to sleep (occurring after 10pm and/or before 6am) occurred in 13 diaries (seven mothers), ranging from one interruption reported in six diaries to five interruptions experienced over both 24 diary periods by a mother with two children aged less than 2 years, one of whom required additional care overnight. Five mothers spent time awake overnight, ranging from 5 minutes to 2.8

hours (see example Box 3). These awake times were all associated with prior care provision for a child.

Box 3: *She can be good and then she can have a bad week. This week she went to bed at 7, she was awake at 10, she was still awake at 2 and when I got up at 6 she was awake. I'm don't know if she'd been asleep between 2 and 6* (SC11)

Table 6.3: Maternal time (in minutes) spent in broad ABS categories

SC	Sleep	Primary personal care	Secondary personal care	Work	Primary domestic	Secondary domestic	Primary communicating family/friends (not children)	Secondary communicating family/friends (not children)	Primary recreation	Secondary recreation
SC1 day 1*	440	45	5	0	325	110	5	5	230	5
SC1 day 2	535	65	15	420	125	60	5	0	65	70
SC4 day 1*	305	120	5	0	180	0	20	175	140	80
SC4 day 2	345	120	45	0	340	25	20	50	70	180
SC5 day 1	565	45	0	345	245	0	20	10	50	110
SC5 day 2	320	70	15	380	205	55	25	45	115	20
SC8 day 1	405	90	10	0	370	10	20	25	195	155
SC8 day 2*	330	105	0	0	145	75	25	110	305	295
SC9 day 1	450	35	0	120	210	30	15	5	100	160
SC9 day 2*	425	55	0	-	250	35	-	120	110	165
SC11 day 1	400	100	5	330	150	45	10	90	55	80
SC11 day 2	420	105	15	0	310	75	20	50	100	25
SC13 day 1	340	40	0	0	170	0	10	125	215	65
SC13 day 2*	375	60	0	0	130	0	200	130	225	15
SC19 day 1	595	70	20	350	240	55	0	5	0	25
SC19 day 2*	570	165	115	0	475	170	0	25	90	40
SC20 day 1	415	115	0	0	215	20	5	55	125	130
SC20 day 2*	510	100	0	0	485	0	25	10	35	215
SC24 day 1	450	115	5	0	410	110	90	145	100	95
SC24 day 2*	620	120	45	0	295	20	5	80	120	130

*weekend day

Table 6.4: Maternal time (in minutes) spent in simultaneous (primary + secondary) activities

SC	Primary + secondary childcare	Child care sole activity	Domestic + childcare	Childcare + domestic	Personal/ recreation + childcare	Childcare + personal/ recreation	Domestic + personal/ recreation	Recreation/ personal + domestic	Activity for CCN sole activity	Activity for other child sole activity	Activity for self sole activity	Activity for self sole activity (pre 9pm)
SC1 day 1*	130	70	250	80	145	10	0	5	20	15	120	0
SC1 day 2	35	110	55	25	65	55	10	5	70	15	60	60
SC4 day 1*	130	365	75	0	30	30	45	0	330	30	120	40
SC4 day 2	40	325	30	0	15	120	25	0	290	35	180	105
SC5 day 1	100	60	125	0	0	10	80	0	40	15	95	95
SC5 day 2	70	30	80	40	20	15	10	0	5	15	140	95
SC8 day 1	215	95	195	5	90	30	20	0	15	55	150	55
SC8 day 2*	90	145	55	30	130	75	0	0	30	80	175	90
SC9 day 1	185	160	160	20	110	130	25	0	65	15	0	0
SC9 day 2*	150	125	215	10	75	155	0	0	35	20	40	0
SC11 day 1	175	60	60	10	25	40	0	20	50	0	65	65
SC11 day 2	215	240	235	25	90	10	0	40	35	165	35	30
SC13 day 1	330	190	155	10	35	60	0	0	135	55	165	140
SC13 day 2*	205	145	75	0	110	5	0	0	110	35	180	75
SC19 day 1	60	80	110	25	35	0	25	0	45	35	35	35
SC19 day 2*	35	35	255	25	145	20	0	30	0	5	80	80
SC20 day 1	90	230	65	5	65	30	30	5	170	60	125	60
SC20 day 2*	40	235	105	0	40	5	195	0	170	65	85	60
SC24 day 1	125	55	195	50	95	15	50	30	20	35	40	5
SC24 day 2*	175	40	110	5	190	10	70	0	15	15	120	75

*weekend day

Table 6.5: Summary of maternal time spent in broad ABS categories and simultaneous activities per 24 hour period (20 diaries)

Type of activity (broad)	Classification of activity	Median (minutes)	Range (mins) minimum to max
Sleep (per 24 hours)		420	(305 to 620)
Personal care	Primary	95	(35 to 165)
	Secondary	5	(0 to 115)
Recreation/leisure	Primary	105	(0 to 305)
	Secondary	80	(5 to 295)
Work[a]		347.5	(120 to 420)
Domestic &/or household related	Primary	242.5	(125 to 485)
	Secondary	32.5	(10 to 170)
Childcare related	Primary	365	(140 to 650)
	Secondary (active)	252.5	(95 to 540)
	Secondary[b] (all, day only)	355	(95 to 650)
Primary domestic/household related & secondary childcare		110	(30 to 255)
Primary childcare & secondary domestic/household related		10	(0 to 80)
Primary childcare & secondary personal care/leisure		25	(0 to 155)
Primary personal care/leisure & secondary childcare		70	(0 to 190)

[a]six diary days (5 participants); [b]does not include passive childcare overnight

6.3.3 Time spent in childcare related activities

An overview of time spent in childcare related activities by the mothers is presented in Table 6.6. More detailed information relating to time spent in specific childcare related activities is presented in Table 6.7.

There was wide variation in the amount of time spent in childcare generally and in specific categories of childcare. The median amount of time spent in primary childcare

was 365 minutes (6.1 hours) with a minimum of 2.3 hours and a maximum of 10.8 hours (Table 6.5 and Table 6.6). When childcare time was widened to include both primary and secondary childcare (passive childcare not included), the median amount of time in childcare related activities per 24 hour period was 11.1 hours (minimum 5.5 hours and maximum 17.1 hours). If passive childcare throughout the day (not including passive childcare at night while the mother slept) was included, the minimum amount remained 5.5 hours but the maximum increased to 19.9 hours per 24 period (median 11.9 hours).

6.3.3.1 Primary vs secondary childcare

Childcare occurred more frequently as a primary activity in the majority of diaries (60%), although six mothers had at least one diary day (nine diaries in total) where the time spent in secondary active childcare (passive childcare not included) was higher than the time spent in primary childcare (Table 6.6). Six of those diary days came from mothers of a child with ASD. This increased to 11 diary days (eight mothers) when secondary passive childcare during the day (ie. not while the mother was sleeping) was included (Table 6.6).

Childcare frequently occurred as a simultaneous (both primary and secondary) activity (Table 6.4). At least 50% of the time spent in primary childcare included a secondary childcare activity in five diary days (four mothers) and between 25-49% of primary childcare occurred simultaneously with secondary childcare in nine diary days (seven mothers).

Table 6.6: Overview of maternal time (in minutes) spent in childcare related activities

SC	Total primary childcare	Secondary childcare (not passive childcare)[a]	Secondary childcare (+ day passive)[b]	Secondary childcare (+ all passive)[c]	Primary time for/with CCN	Primary time for/with other child	Secondary time for/with CCN	Secondary time for/with other child
SC1 day 1*	290	375	650	650	355	60	260	345
SC1 day 2	225	105	185	185	155	40	30	40
SC4 day 1*	650	235	235	235	580	60	155	80
SC4 day 2	520	95	95	95	435	45	30	40
SC5 day 1	170	225	225	225	95	65	160	65
SC5 day 2	155	175	175	175	150	15	65	90
SC8 day 1	360	525	525	525	100	170	70	360
SC8 day 2*	395	270	320	320	95	225	35	185
SC9 day 1	505	230	610	1060	190	100	80	155
SC9 day 2*	540	175	500	990	230	35	15	130
SC11 day 1	390	270	290	615	150	115	100	110
SC11 day 2	485	540	575	885	235	280	20	370
SC13 day 1	635	330	560	850	440	140	45	215
SC13 day 2*	370	235	405	810	260	115	-	35
SC19 day 1	185	205	205	205	100	65	65	85
SC19 day 2*	140	435	435	435	30	35	95	120
SC20 day 1	510	300	300	775	340	165	160	50
SC20 day 2*	285	195	195	705	320	140	120	30
SC24 day 1	275	435	435	840	100	120	145	120
SC24 day 2*	280	390	390	1015	90	100	245	100

*weekend day

[a]Does not include passive childcare during day or night

[b]Does not include passive childcare overnight

[c]Includes passive childcare overnight

6.3.3.2 Patterns of childcare

For the majority of mothers (60%) the time spent in childcare was consistent (no more than 60 minutes time difference in primary childcare across the two diary days). There was no clear pattern emerging for the amount of time spent in primary childcare on weekdays versus weekend days. Five of the eight mothers who completed a weekend day diary spent more time in childcare on weekend days, the increased time spent in primary childcare related activities ranging from 5 minutes to 130 minutes (median 35 minutes). The remaining three mothers spent more time in childcare on weekdays, the increased time spent in primary childcare related activities on weekdays ranging from 45 minutes to 265 minutes (4.4 hours).

Mothers of children with more severe conditions and/or requiring more assistance with activities of daily living such as eating, dressing, hygiene and locomotion (indicated by the presence of multiple morbidities and/or a higher AAQ score) spent high amounts of time in primary childcare. For example, the five mothers of children with an AAQ score of 17 or above (indicating the need for a high level of assistance) all recorded at least one diary day with a minimum of 8 hours spent in primary childcare. This was a consistent pattern irrespective of the number of children in the family or the age of the child with complex needs. An example of diary excerpts illustrating primary and secondary childcare from two of these mothers is presented in Figure 6.5.

Figure 6.5: Diary excerpts from mothers of children with multiple morbidities and high need for assistance

Excerpt 1

Time	What were you doing?	Who did you do this for?	What else were you doing at the same time?
0705	Put clothes on the line	Self	Passive childcare
0710			
0715	Checked emails		
0720	Gave puffers	Child 2	
0725	Woke son up	Child 3	Said goodbye to husband
0730	Ate breakfast	Self	
0735	Dressed child, changed nappy	Child 4	
0740			Talked to child 1,3,4
0745	Bladder/bowel massage	Child 2	
0750	Change nappy		
0755	Give medications		
0800	Give puffers		
0805	Put body splint on		
0810	Dressed son		
0815	Prepared wheelchair		
0820	Put child in wheelchair		
0825	Suctioned child		
0830	Put children in van	Child 1,2,3,4	
0835	Drove to school	Child 1,2,3	Listened to radio

[a]child numbering system as allocated by mother when completing the diary. Child 2 is child with complex needs

Excerpt 2

Time	What were you doing?	Who did you do this for?	What else were you doing at the same time?
1620	Put on load of washing	self	Take child 3 to toilet
1625	Check school bag	Child 1	
1630	Read note from teacher		Listen to music practice child 2
1635	Carry from couch to bedroom		
1640	Talk to support worker		
1645	Get soup out of freezer	Everyone	
1650	Defrost soup for tea		
1655	Carry to bathroom	Child 1	(to support worker)
1700	Listen to home reader	Child 2	Watch child 3 try to do somersaults!!
1705			
1710			
1715	Hang washing on clothes horse	self	
1720	Prepare scrambled eggs	Child 1	
1725	Carry to bedroom	Child 1	Undress child 3 & put in bath
1730	Give medication	Child 1	
1735	Cook scrambled eggs	Child 1	Child 2 to shower
1740	Give eggs to support worker to feed to child 1	Child 1	Talk to husband
1745	Get out of shower	Child 2	Get PJs ready for child 2&3
1755	Get out of bath	Child 3	

[a]child numbering system as allocated by mother when completing the diary. Child 1 is child with complex needs

Four of the five mothers who recorded the lowest amount of time spent in primary childcare activities had a child with ASD, the fifth mother had a child with global developmental delay (GDD).

The highest amount of time spent in active childcare as a secondary activity (nine hours) was recorded by a mother of a child with Rett syndrome who had two siblings, including one two years of age. The five diary days that recorded the next highest amounts of time spent in active childcare as a secondary activity (ranging from 6.3 to 8.8 hours)

were from mothers (n=4) of children with ASD or GDD. Diary excerpts from two of these mothers illustrating the types of secondary childcare related activities that were occurring are presented in Figure 6.6**.**

Figure 6.6: Examples of time use diary entries from two mothers of a child with ASD

Excerpt 1

Time	What were you doing?	Who did you do this for?[a]	What else were you doing at the same time?
1620	Sat down with child 2	child 2	Constant question answering from child 2 – running backwards & forwards from child 2s bedroom. Helping child 1 with homework in between[b]
1625	↓		
1630			
1635	Vacuumed house	family	
1640			
1645	↓		
1650			
1655	Prepared child 2's meal	child 2	
1700	Organised washing	family	
1705			
1710	↓		
1715	Dressed child 2 for bed		

[a]child numbering system as allocated by mother when completing the diary. Child 2 is child with complex needs [b]as written by the mother

Excerpt 2

Time	What were you doing?	Who did you do this for?[a]	What else were you doing at the same time?
1600	Open curtains, put heater on	Self ↓	Talking to child 1&2
1605	Made lunch for husband, drink tea		Talking to child 2
1610	Sort dirty washing & put in machine		Talking to child 1, 2 & husband
0710	Talk to husband, cuddle child 1&2	↓	—
0715	Prepared breakfast	Self, child 1&2	Talking to child 1 about what we are doing today (again) ←
0720	Clean up spilt breakfast from child 2	Self	Calming down child 1 that its ok to spill breakfast
0725	Ate breakfast		Assist child 1 with eating
0730	↓	↓	Talking with child 1 about what we are doing today (again)
0735	↓	↓	↓
0740	Sort clothes off clothes dryer	↓	Talking to child 1 & 2

[a]child numbering system as allocated by mother when completing the diary. Child 1 is child with complex needs

6.3.3.3 Recipient of childcare related activities

There were five diary days from three mothers where the primary childcare related time spent with another child was higher than the primary childcare related time spent with the CCN (Table 6.6). In all three families, the child with complex needs had a sibling aged less than four years. Two of these families had three children.

A different pattern emerged when considering secondary childcare (but not including passive childcare occurring overnight). In 14 diary days from eight mothers, the secondary time spent with another child was higher than the child spent with the child with complex needs (Table 6.6 and see example Box 4)

> **Box 4:** *And that's what I do for the other two but it just takes so much longer and on the nights I'm doing it with [daughter] then the other two seem to just sort of follow along and get less attention. I don't think they miss out (SC11)*

6.3.4 Types of childcare related activities

6.3.4.1 Physical childcare

Time spent in primary physical childcare ranged from 25 minutes to 4.6 hours (median 125 minutes). This time was consistently higher than the time spent in other categories of primary childcare related activities in the diary days, although there were three exceptions to this:

1) three mothers of children with ASD (SC1, 5, 24) spent more primary activity time engaging with their child/children on at least one diary day

2) one mother of a child with multiple morbidities (SC13) spent more primary activity time in healthcare related activities on both diary days

3) one mother (SC20) spent more primary activity time in one diary day on 'other' child related activities, which included spending a significant amount of time (2.7 hours) providing parent help at her child's school and attending a structured kinder play session with her younger child.

Time spent in primary physical care activities was associated with a higher need for assistance in the child with complex needs (see example Box 5). The six diary days with the lowest amount of time spent in primary physical care came from three mothers whose child with complex needs scored 12 or lower on the AAQ.

Box 5: *…she'll take 20 mins or half an hour to eat but at the end of the day she's really tired and it can take an hour…if she puts her head forward it might fall out and if she gets too salivary she'll choke on it so you give her a mouthful and watch she's chewed it and started it and then can do something else… but remain in close contact (SC11)*

6.3.4.2 Engaging with child

Engaging with a child included activities that could be classified under categories 521 and 531 of the ATUS (Australian Bureau of Statistics, 2008) such as playing, reading, talking to a child and helping a child with an activity. For some mothers, engaging with their child with complex needs as a primary activity included the mother undertaking therapy or providing an additional layer of care with their child as an embedded activity, at times almost as an unconscious action (see example Box 6).

Box 6: *…just what you do, part of the routine…if I'm sitting next to her, her thumbs get quite tight and her hands and I'll just be sitting there playing with her hands and stretching out her fingers. I don't really think about it, I just do it (SC11)*

Two mothers specifically described embedding therapy with their child into play activity. One mother of a child with cerebral palsy included the following comment on her diary:

Please note, where I have put 'playing with children' this includes a lot of physio play for child 1 which I have not had enough room to specify. Let me know if you need more info (SC9)

When this was followed up with the mother over the phone, she estimated that 80% of the time spent playing with her child with complex needs involved physiotherapy incorporated into the play.

Another example is provided in the following diary excerpt from a mother of a child with ASD (child 1 is the child with complex needs):

Time	**What were you doing?**	**Who did you do this for?**	**What else were you doing at the same time?**
1125	Build train track with child 1* ↓		Reading books to child 2 ↓
1130			
1135	Toilet stop for me & child 2		nothing
1140	Playing trains with child 1* ↓		Reading more books to child 2 ↓
1145	↓		↓

Written at the bottom of the diary page: **child 1 is currently partaking in the play project and I am using this in his play time*

Engaging with a child was the category of childcare requiring the highest time as a secondary activity in the majority of diaries (n= 14, 70%) (Table 6.7). The exception to this was one mother who spent more time in physical care as a secondary activity (SC19) and three mothers (SC9, 13, 20) who had at least one diary day where actively supervising their child/children as a secondary activity required a higher time commitment.

Six diary days from five mothers (SC 1, 5, 8, 11, 24) included relatively high amounts of time spent engaging with a child as a secondary activity (range 3.6 to 5.1 hours). Four of these (SC1, 5, 8, 24) were the mother of a child with ASD (see example Box 7). Although secondary engagement activities occurred with all children, the majority of the time spent in engagement activities involved the child with ASD for three of these mothers, specifically 65% of secondary engagement time for SC1 (56% as sole child involved); 74% for SC5 (as sole child involved); and 79% for SC24 (25% as sole child involved).

Box 7: *From the time he wakes up until the time he goes to bed…it's always a lot of verbal contact with him (SC5)*

The remaining mother (SC8) spent the majority of the time engaging with her youngest child (not the child with complex needs) during the day while the other children were at school – only 10% of the secondary engagement activities involved the child with ASD.

6.3.4.3 Healthcare related childcare activities

There was a consistent pattern of higher amounts of time spent in healthcare related activities when the child had more complex needs or a higher assistance requirement (indicated by the presence of multiple morbidities and/or a higher AAQ score). The time spent in healthcare by the mothers of these children (SC1, 4, 9, 11, 13, 20) ranged from 25 minutes to 5.2 hours (median 2 hours) (Table 6.7). The remaining mothers spent minimal or no time in healthcare related activities across both diary days (maximum 10 minutes). All were the mother of a child with ASD or GDD.

There was wide variability in the types of healthcare related tasks. Some activities occurred more commonly in the 15 diary days that contained healthcare related childcare activities, including preparing and administering medications (n=15 diaries, 100%), monitoring seizures (n=3, 20%), physiotherapy (n=4, 27%), applying a splint or brace (n=3, 20%), and pressure area care/positioning (n=5, 33%).

6.3.4.4 Additional childcare requirements for child with complex needs

There was a wide variation in the amount of time the mothers spent undertaking/performing activities that could be inferred as being additional activities required to meet the needs of the child with complex needs, ranging from 15 minutes (SC24) to 7.5 hours (SC4). The highest additional time requirements occurred in diary days from mothers of children with multiple morbidities and/or high need for assistance (AAQ score 17 or higher). For these five mothers (SC1, 4, 9, 11, 13, 30) the median additional care time was 170 minutes (2.8 hours) with a minimum of 1.9 hours and maximum 7.5 hours.

Table 6.7: Breakdown of time (in minutes) spent in childcare related activities

SC	Physical childcare	Secondary physical childcare	Primary emotional childcare	Secondary emotional childcare	Primary healthcare related	Secondary healthcare related	Primary engaging with child	Secondary engaging with child	Primary active supervision	Secondary active supervision	Primary other childcare	Secondary other childcare
SC1 day 1*	75	25	70	80	25	-	40	270	50	-	30	-
SC1 day 2	25	30	5	-	30	10	80	40	-	20	85	5
SC4 day 1*	210	-	-	-	205	5	75	170	75	60	80	-
SC4 day 2	145	-	75	5	125	-	15	60	25	30	130	-
SC5 day 1	70	10	15		10	-	50	215	-	-	25	-
SC5 day 2	55	20	20	-	-	-	70	140	-	-	10	15
SC8 day 1	185	150	15	20	-	-	35	305	10	25	100	25
SC8 day 2*	175	45	55	20	5	-	105	135	-	70	50	-
SC9 day 1	255	40	60	5	115	20	70	65	-	100	-	-
SC9 day 2*	275	25	65	-	160	-	40	-	-	150	-	-
SC11 day 1	120	55	10	-	125	45	30	155	25	5	80	10
SC11 day 2	180	45	45	-	90	20	115	265	-	210	50	-
SC13 day 1	140	-	5	10	310	35	30	130	20	150	125	5
SC13 day 2*	125	-	25	-	210	-	-	150	-	85	10	-
SC19 day 1	90	120	-	-	-	-	-	55	-	20	95	10
SC19 day 2*	125	220	-	-	-	-	-	65	-	150	15	-
SC20 day 1	125	20	20	5	55	35	40	110	15	100	255	30
SC20 day 2*	140	10	10	15	25	15	80	20	15	135	-	-
SC24 day 1	45	15	30	40	-	10	200	280	-	60	-	30
SC24 day 2*	80	45	45	30	5	-	150	310	-	5	-	-

*weekend day

6.4 Discussion

This is the first study to date that details how mothers divide the time they spend in childcare related and other activities within a 24 hour period, between all of their children, including a child with complex needs, and for both primary and secondary activities. A strength of the study is the ability to quantify the substantial component of the overall daily time that mothers spend in childcare related activities specifically to address the needs of their child with complex needs.

A number of conclusions are suggested by the findings from the 20 diaries completed by this sample of 10 mothers of children with complex needs: 1) mothers of children with complex needs spend substantial amounts of time in childcare related activities; 2) secondary childcare frequently involves actively engaging with at least one child and this is a consistent pattern in families with a child with ASD; 3) mothers of children with severe conditions or requiring more assistance with ADLs spend substantial amounts of time in physical and healthcare related childcare activities; 4) more time is spent undertaking primary childcare activities for or with the child with complex needs than with other children in the family; 5) time spent by mothers in personal care or recreation/leisure activities is frequently combined with domestic or childcare related activities; and 6) primary domestic/household activities undertaken by mothers are frequently combined with childcare related activities.

The median time spent in primary childcare by mothers in this study was 365 minutes per 24 hours, although there was extremely wide variation in the time spent in both primary and secondary childcare across the sample. At first glance this appears less than the 44.1 and 45.7 hours per week (extrapolated as 378 and 392 minutes per day) spent in childcare by parents in the national ATUS conducted in 1992 and 2006 respectively (Craig et al., 2010). However, the multivariate analysis use to calculate these national results did not distinguish between primary and secondary childcare activities (Craig et al., 2010). The frequent simultaneous occurrence of childcare activities in the current study means that comparative figures (all primary and secondary childcare) cannot be calculated for the 20 diary days, but the considerable amounts of time spent in

secondary childcare would suggest that the overall childcare time was substantially more for the mothers of children with complex needs. This difference is clearly apparent if comparing the median 508 minutes per 24 hours spent in primary childcare by the five mothers of children who had more complex needs and a higher assistance requirement (indicated by the presence of multiple morbidities and/or an AAQ score of 17 and above). On average, these mothers spent almost two hours more in childcare per day than the 2006 population results, without taking into account the substantial amount of secondary childcare that was also occurring.

Under normal circumstances, the time spent in childcare related activities in a one child family declines as the child grows older, decreasing from 91.2 hours/week for infants, to 70.8 hours for children aged 5-9 years and down to 30.4 hours for children aged 13-14 years (Ironmonger, 2004). While this is an expected pattern occurring in conjunction with the increasing maturity of the child, it does not occur in families with a child with complex needs, the needs of those children remaining constant, or potentially even increasing as they grow larger and heavier, particularly if the child's condition is associated with deterioration and/or loss of function over time. A proxy measure of this altered pattern in families of children with complex needs is the time spent in child related activities that are additional care requirements directly related to the complex needs of the child – care over and above the care that is normal for a child's age (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993).

Different patterns of time spent in childcare do emerge from the current study based on the diagnosis and/or requirements for assistance of the child. Mothers of children with ASD or GDD recorded more time spent in secondary active (passive not included) childcare than in primary childcare. The median primary childcare time for this group of mothers (250 minutes) is lower than the childcare time reported in a study with mothers of children with ASD that also used the ATUS to record the time use of the mothers over one 24 hour period (Sawyer et al., 2010). However, the mean time reported for that study (372 minutes) was described as the total amount of time spent caring for the child in a 24 h period (Sawyer et al., 2010) and no information was provided regarding

whether this constituted primary time only or included secondary childcare, making comparisons difficult.

A reverse pattern of time use was observed in the remaining five mothers who all had children with a higher assistance requirement (an AAQ score of 17 and above). For these five mothers, primary childcare activities occupied substantially more time than secondary active childcare. More than a third of the 24 hour period was spent in primary childcare in at least one diary day for these mothers irrespective of the number of children in the family or the age of the child with complex needs. Stratifying analysis according to whether children have functional limitations is recommended for research with children with chronic conditions in order to highlight the needs of the most affected group (Davis & Brosco, 2007). Sub group analysis is not possible in this study, but the pattern of increased time use for mothers of children with the greatest functional limitations based on the AAQ score supports similar findings from other time use studies in this population (see for example Brust, Leonard, & Sielaff, 1992; Leonard, Brust, & Sapienza, 1992; Smith, 1986), although no correlation between time spent in childcare and level of severity has also been reported (Lampropoulou & Konstantareas, 1998; Lucca, 1990).

Parents of children with complex needs describe 'centripetally organised routines', family routines that are organised around the child with complex needs to an extent that is not expected or usually seen in other families with children, particularly as the children grow older (Larson & Miller-Bishoff, 2014). The care of the child with complex needs is the central organising feature and other activities are selected as complementary to it or balanced against the needs of that child (Cant, 1994; MacDonald, 1995; Olsson & Hwang, 2003). This is a clearly seen in the current study, a pattern emerging of care of the child with complex needs occurring more as a primary activity while childcare related activities with/for other children in the family are more commonly secondary activities, particularly when the child with complex needs requires higher amounts of assistance with daily activities or has significant treatment/therapy requirements. The only diary days where this pattern did not occur was in families with

at least one sibling aged less than four years, these children having additional care requirements due to their developmental stage.

How well parents meet the needs of all their children when at least one of the children has complex needs is poorly understood, particularly when the child with complex needs is an adolescent (Koch & Mayes, 2012). But despite the significance of this issue, differentiation between the care of child with complex needs and the care of other children in the family is rarely reported in time use research and not collected for the majority of studies. Care of other children was recorded in a study with parents of children with disabilities, but only in the 'Other activities' section of the diary and not included in the analysis of time spent in childcare related activities, although mention is made of the fact that childcare for other children in the family was undertaken concurrently with care of the child with a disability in most cases (Crettenden, 2008). More recent research recorded the time parents of children who were technology dependent or had ASD spent with their study child and compared this to time spent with their partner and/or other children, but this represented being in the presence of the child or children rather than undertaking childcare related activities for or with the child (Thomas, 2011). This is the first time use study with parents of children with complex needs that is able to differentiate the care provided to the child with complex needs compared to other children in the family at the activity level. These findings provide a level of insight missing from previous research in this area and confirm that children with complex needs, particularly those with high needs, require a substantial amount of their parent's time and that this has the potential to impact on the amount (and perhaps the quality) of time available to siblings and other members of the family.

Simultaneously occurring activities are a feature of all of the diaries from the ten mothers participating in this study. Primary childcare activities were frequently combined with a secondary childcare related activity (at least 50% of the primary childcare related activities were combined with a secondary childcare related activity in a quarter of the diary days). This is a much higher percentage than was found in an examination of a random sample of records from 10 female carers in the 1997 ATUS, childcare recorded as a simultaneous primary and secondary activity on only 6% of

occasions in that sample (Crettenden, 2008). While it is difficult to draw comparisons due to the lack of available information in this area, the fact that mothers in the current study are frequently undertaking simultaneous childcare activities suggests a need to combine childcare related activities in order to meet the needs of all children and highlights the intense nature of providing care to children when one of them has additional complex needs.

What becomes clear when examining the diary days is the significant amount of time mothers spend undertaking combinations of activities throughout the day. Recreation and personal care activities are combined with domestic or household duties and childcare is frequently combined with domestic or household related activities, recreation activities and with other childcare. This echoes the findings of time use research in the general population, where a very high proportion of the care given to children is happening at the same time as other activities, parents recording twice as much time spent in childcare as a secondary activity as that spent in primary activity childcare (Craig & Bittman, 2008). The combination of housework and childcare activities accounts for 10.1% of all multitasking episodes for mothers generally (Offer & Schneider, 2011), but the percentage of time spent in this combination of activities is higher for the mothers of children with complex needs represented in this study.

There is often a sense of fun apparent in the diary descriptions provided for activities where mothers engage with their children. While not disregarding the enjoyment gained from these interactions, the intensity of the child related caregiving for the mothers in this study is compounded by the relative lack of opportunity to relax and take time for themselves across the 24 hour period. Pure leisure has been defined as a lack of simultaneous activity and the absence of children for whom the adult could be considered responsible (Thomas, 2011). Another study describes 'Me time' for mothers as restorative, autonomous time spent away from the responsibilities of caregiving because children are safely and sufficiently occupied (Larson & Miller-Bishoff, 2014). Mothers in the current study had very little pure leisure or me time based on these definitions. Recreation activities were frequently combined with childcare or domestic duties (eg. watching television while sorting washing). In 80% of the diaries, the mothers

spent 10% or less of their time in personal care or recreation activities as sole activities (not combined with another activity). The fact that personal care activities are combined with recreation in these figures highlights the very little time the mothers spent in pure leisure time, enjoying recreation as a sole activity with no responsibility for children. None of the mothers enjoyed pure leisure time outside the home with the exception of one mother who went to the gym and used the onsite childcare facility to provide care for her youngest child. This lack of pure leisure time, combined with the intensity associated with the frequently simultaneous activities undertaken by the mothers, raises concerns about the impact on their health in the longer term.

In its simplest form, multitasking is when an individual undertakes more than one unrelated activity at the same time, the two key criteria being task independence and performance concurrency (Benbunan-Fich 2012). It can be conceptualised as a broadening of time, whereby time is seen as a horizontal as well as a vertical entity (Kenyon, 2010). Multitasking can bring benefits in terms of increased individual productivity, but the trade-off is the intensification of work, and the potential for higher levels of stress and less pure leisure time (Miller & Bowd, 2012). The increased urgency and pressure associated with simultaneous activities or an increased layered-task structure (combining more, often fragmented tasks into single time units) may adversely affect personal well-being, particularly for those with monochronic personalities or a tendency toward monochronic behaviour (Floro & Miles, 2003; Rubin, 2007). Multitasking plays an important role in mothers' experiences of emotional stress in the general population of parents (Offer & Schneider, 2011). The need to multitask and deal with frequent interruptions and time pressures is listed by nurses as a contributing factor in their physical and mental fatigue (Steege, Drake, Olivas, & Mazza, 2015). For the mothers of children with complex needs, the multitasking may be so common as to become almost an unconscious action. The mothers described a process of embedding care into engagement activities with their children, incorporating physiotherapy and other forms of therapy into play, while changing a nappy or while sitting with their child. Descriptions of these embedded activities were captured in the diaries, but also expanded on by the mothers in notes accompanying the diaries and in the interviews with the two key informants. This embedded care was not restricted to

any particular group or diagnosis within the sample, but instead was represented throughout the study population.

6.4.1 Strengths and limitations

This study was limited by the small sample size (20 diaries from 10 mothers of children with complex needs) and thus detailed statistical analysis and subgroup comparisons were not possible. However, the fact that the mothers all completed two 24 hour free form diaries using an internationally highly regarded tool and including both a weekend day and weekday for most participants is a strength of this study. Other studies have chosen to use precoded or predefined diaries rather than free form (see for example (Crettenden, 2008; Thomas, 2011), thus reducing the burden on participants but decreasing the amount of information and level of detail that is available regarding the type of activities parents are undertaking.

What this small sample size has enabled is a level of analysis not previously reported in time use research in this area and a comprehensive description of the types of activities undertaken by mothers caring for a child with complex needs and other children. Although previous time use studies have provided a detailed overview of time spent in specific categories of childcare related activities such as healthcare related activities (see for example Moskowitz et al., 2007; Wilson et al., 2005) few time use studies with parents of children with complex needs detail the range of childcare related activities that parents undertake on a daily basis and the recipient of these activities. This study addresses these existing gaps by providing: 1) a detailed description of the time spent by mothers of children with complex needs in a range of childcare related activities over a 24 hour period; 2) differentiating between time spent in childcare with/for a child with complex needs and other children in the family; 3) differentiating between primary and secondary childcare related activities based on the type of task and the characteristics of the child with complex needs; and 4) a detailed analysis of the combinations of activities that mothers of children with complex needs engage in within a 24 hour period. The reliability of the ATUS coding system used in the time use study has been established in national time use surveys with the Australian population, but reliability testing of the amended ATUS codes that were developed to enable the detailed analysis

has not occurred and was logistically not possible due to the unacceptable load that performing a test retest would have placed on the study participants.

The response rate for the study was low, including only a 50% response rate from parents who indicated their willingness to participate and received the full study pack, reducing the generalisability of the findings. While a number of factors may have contributed to this, the key reason communicated by non-participants was (ironically) lack of time to participate. This is a common finding in research in this area. Parents of children with cerebral palsy were too tired or busy to participate in a study exploring sleep disturbance in their children (Petersen et al., 2015) Parents of children in educational facilities for children with special needs gave lack of time as a reason for not completing a survey, the parents not having time for anything that was not mandatory (Raver, Michalek, & Gillespie, 2011). A time use study using the ATUS with parents of children with ASD was based on a single 24 hour diary because pilot testing had shown any additional diary days placed an unreasonable burden on mothers who were already very busy caring for their children (Sawyer et al., 2010). Even the single diary day was too onerous for several mothers who declined to participate because they were too busy (Sawyer et al., 2010).

The fact that some parents indicated verbally and in writing that they were unable to participate in the current study due to time constraints may mean that the results underestimate the time pressure and total hours of caregiving required (Sawyer et al., 2010). This is a cause for concern when considering the significant amounts of childcare related time reported in previous studies (McCann et al., 2012) and the time spent in primary and secondary child related activities by some mothers in this study.

6.5 Conclusion

The level of detail obtained from the 20 diaries in this time use study addresses deficiencies identified in previous research in this area (Jowsey, Yen, & Mathews, 2012; Painter, Rausch, & Modi, 2014; Thomas, 2011). Emerging from these detailed findings

is a picture of mothers of children with complex needs spending a substantial amount of time in childcare related activities that are often combined with other childcare related activities, domestic or household related activities, or maternal self-care or leisure time. Patterns exist within the data, including substantial amounts of time spent in primary physical and healthcare related activities for mothers of children with severe needs or increased functional limitations, and high amounts of time spent engaging with children with ASD as a secondary activity. Both these patterns suggest an intensity of caregiving that is poorly captured in current time use research.

This study quantifies for the first time the amount of time that mothers spend in primary childcare activities for their child with complex needs and for other children in the family. While caution needs to be exercised in interpreting these findings, the data from this study appears to confirm that higher amounts of time are spent in primary childcare related activities for or with a child with complex needs, the other children in the family receiving more care as secondary childcare related activities. This has implications for the parents providing the care, and for the children adapting to a world where routines and activities are frequently structured around the care requirements of their sibling with complex needs.

Parents of a child with complex needs describe the joy their child brings to the family and the enjoyment they gain from providing care for them. But the parents also describe being exhausted and worn down by the intense 24 hour nature of the caregiving. By providing previously unavailable levels of detail regarding the type and combinations of care that is provided by mothers of a child with complex needs, this study suggest possible reasons for the care burden described by parents in this area, particularly when placed in the context of the relatively little time the parents have to care for themselves. It also reinforces the need to provide opportunities for parents to gain respite in a form that works for them and their family, allowing the parents to maintain what is in some cases a truly remarkable level of care without having a serious impact on their own physical, emotional and mental health.

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Chapter 7 - Competence, value & enjoyment of childcare activities

Chapter 7 consists of a paper accepted for publication as a brief report in *Journal of Pediatric Nursing*. The focus of the paper is how mothers rate the importance of activities undertaken with their children and their enjoyment and competence in performing these activities. While the paper focuses on activities undertaken with all children in the family, there is a focus on activities undertaken with or for a child with complex needs, with an emphasis on healthcare related activities. The activities rated in this study are taken from the time use diaries completed by mothers in the time use study reported in Chapter 6.

7.1 Abstract

Objective: Parents combine many roles when caring for a child with complex needs, but few studies measure parental value and enjoyment of childcare related activities.

Method: Ten mothers of children with complex needs rated their competence, value and enjoyment of 156 childcare related activities using the Occupational Questionnaire (Smith, Kielhofner, & Hawkins Watts, 1986).

Results: The mothers rated childcare related activities as important and rated themselves as competent to undertake them. Mothers disliked performing healthcare related activities, but enjoyed emotional care activities.

Conclusion: This study extends current knowledge regarding role tension described by parents of children with complex needs and may enable paediatric nurses to better understand the impact of home based care provision on parents.

7.2 Introduction

Parents combine multiple, often contradictory roles when caring for a child with complex needs (CCN) including parent, advocate, educator, case manager, nurse and physiotherapist (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Whiting, 2014). Time use research describes the amount of time spent in childcare related occupations, but there is limited information about the parents' perceptions of their engagement, meaningfulness, enjoyment and satisfaction with these activities (Gevir, Goldstand, Weintraub, & Parush, 2006; Lampropoulou & Konstantareas, 1998). The Australian Time Use Survey is unusually comprehensive, but records only behaviour, with no measure of how respondents feel about what they do (Craig, 2006).

The additional care requirements involved in caring for a CCN and the impact on parents is well documented (eg. Sanders, Bray, Driver, & Harris, 2013; Santer et al., 2013; Swallow, Lambert, Santacroce, & Macfadyen, 2011). Relatively few studies however have measured parental perceptions regarding childcare activities (see Table 7.1). Enjoyment of activities has been described (Cant, 1994; Gevir, et al., 2006; Lampropoulou & Konstantareas, 1998; Padeliadu, 1998; Plant & Sanders, 2007) although mainly associated with broad categories and rarely healthcare related activities. This study therefore aimed to describe parental competence, enjoyment and value of childcare related activities, particularly healthcare related activities, when parenting a CCN.

Table 7.1: Examples of studies measuring meaningfulness and enjoyment of childcare activities for parents of children with complex needs

Author/s	Sample[a]	Data collection tool	Variables measured	Classification of child caring	Main findings
Plant & Sanders (2007)	Mothers (n=105) of children with developmental disability	Checklist of 22 childcare related activities	Stress associated with specific activities and Likert scale assessing stressfulness of task completion and difficulty getting activities done	1) Direct care (bathing, feeding, toileting, dressing); 2) in-home therapy; 3) attendance at appointments; 4) supervision of child; 5) play and leisure activities; 6) education and information about disability; 7) advocating for services; 8) managing child behaviour	Mealtimes, cleaning up after child, settling at bedtime, supervising toileting and advocating to health professionals ranked as five most stressful activities on checklist of 22 different tasks. Doing therapy and giving medication ranked 7 and 13 respectively. High stress mothers found caregiving activities more difficult and associated with more difficult child behaviour and lower child functioning.
Gevir et al. (2006)	Mothers of children with mental retardation MR (n=29); motor difficulties MD (n=30); ADHD (n=30); typical development TD (n=31)	Mothers Time Use Questionnaire adapted in part from Occupational Questionnaire	1) Perceived meaningfulness; 2) enjoyment derived	Activities with their children	Most meaningful occupations 'activities with child' and home maintenance, but home maintenance least enjoyable occupation. No significant difference in meaningfulness assigned to activities by different groups. Mothers of children with ADHD had significantly less enjoyment in activities with child.
Lampropoulou & Konstantareas (1998)	Mothers of deaf children (2-14yrs) with no other disabilities (n=42)	Form reporting time spent in child related activities and 'perceived affective tone'	Activities perceived as 'fun', 'neutral' or 'a chore'	1) Dressing; 2) feeding/meals; 3) bathing & toileting; 4) playing & recreation; 5) teaching/education; 6) bedtime routines	Higher stressed mothers significantly more likely to rate dressing and bathing their child and meals as a chore or neutral compared to lower stressed mothers. Mothers undertaking more dressing, bathing, feeding related activities more likely to report lack of enjoyment (neutral or a chore rating). No play/recreation activities given 'a chore' rating
Padeliadu (1998)	Mothers of children (mean age 12.6yrs) with Down Syndrome DS (n=41) & no disabilities ND (n=41)	Form reporting time spent in child related activities and 'perceived affective tone'	Activities perceived as 'fun', 'neutral' or 'unpleasant'	1) Dressing; 2) feeding/meals; 3) bathing & toileting; 4) playing & recreation; 5) teaching/education; 6) bedtime routines	Mothers of children with DS significantly more likely to perceive time demands as 'fun' compared to comparison group ($p<0.001$). Perceiving child demands as 'unpleasant' associated with higher stress for mothers of children with DS ($p=0.001$).
Cant (1994)	Mothers of children (2-15yrs) with cerebral palsy CP (n=53) or spina bifida SB (n=20)	Semi-structured interview accompanying time use diary (24hrs) x4 days	Things parents do for their child that are: 1) least liked; 2) most stressful	1) Maintenance work (physical care & minding); 2) enrichment activities (teaching, helping, playing, reading & talking to child); 3) Travel	Caregiving activities that involved dealing with bodily products (eg. toileting, catheterization, bowel evacuation, teeth cleaning) among the most disliked. Attending to hygiene needs difficult and heavy work for parents of teenagers with cerebral palsy. Teaching activities and taking child to appointments greater source of stress than physical care activities.

[a]Description as stated in original article. **Abbreviations used in table:** ADHD = Attention Deficit Hyperactivity Disorder

7.3 Methods

This pilot study was undertaken as an extension of a time use study with ten mothers of a CCN recruited through local respite services in 2011. As part of their participation in the time use study, each mother completed two 24 hour diaries (n=20) using the Australian Bureau of Statistics (ABS) Time Use Survey (Australian Bureau of Statistics, 2008). The diary is set out in columns that include information about the respondent's primary activity (what they were doing); who they were doing the activity for; and whether they were doing anything else at the same time (secondary activity) (Australian Bureau of Statistics, 2008b). Information is obtained in free form, the participants recording their activities in 5 minute blocks over a 24 hour period. For each childcare activity recorded in the diaries, the mothers indicated the age of child for whom the activity was undertaken and whether the child had complex needs.

7.3.1 Data collection

Data were collected using the Occupational Questionnaire (Smith, Kielhofner, & Hawkins Watts, 1986). The questionnaire contains a column to record activities, with 5 point Likert scales used to rate competence, value and enjoyment of each activity (Smith, et al., 1986). Activities were selected from each mother's time use diary based on criteria (involved care of child/children; discrete task; emphasis on healthcare related activities) and listed in the activities column of the Occupational Questionnaire. Activities undertaken twice with two different children (one CCN) were both included. Activities involving care of CCN were overrepresented, reflecting the higher percentage of these activities. The questionnaire was then posted to the participants and all mothers returned a completed questionnaire.

Test – retest reliability testing for the Occupational Questionnaire demonstrated 81% agreement for activity value, 77% for competence and 77% for interest (Smith, et al., 1986). No study using the full version of the tool with parents of a CCN was located, but an adaptation has been used with parents of children with disabilities to assess meaningfulness of activities (Gevir, et al., 2006).

7.3.2 Data analysis

Descriptive statistics were used to profile competence, enjoyment and importance of activities at the individual participant and the subcategory (emotional care, healthcare, toileting, feeding, hygiene/dressing, engagement with child, supervision) level.

7.4 Results

Data were available for 156 activities (Table 7.3), 104 (67%) with CCN, including 33 (94%) of healthcare activities. Activities were coded into sub categories relevant to the care of CCN (Table 7.2). Categories included physical care (n=54), healthcare (n=35), engagement (n=42), emotional care (n=14) and supervision (n=11). The average number of activities per participant was 16 (range 11–19).

Table 7.2: Description and classification of included activities

Sub categories	Number of activities (%)	Inclusions
Emotional care	14 (9)	Cuddling, comforting, soothing
Healthcare	35 (23%)	Healthcare related treatments and procedures (eg. suctioning, preparing or administering medication, monitoring seizures), healthcare related communication and travel, mobility assistance, positioning (including pressure area care)
Physical care		
Toileting	11 (7%)	Toileting child, nappy/pad change, bowel massage, changing wet bed
Feeding	10 (6%)	Assisted/supervised oral feed, full assistance oral feed, tube feeds
Hygiene/ dressing	33 (21%)	Bathing or showering child, supervising child attending to own hygiene needs, partial or full assistance with dressing
Engagement	42 (27%)	Reading, talking and playing with child, helping or reprimanding child, non-healthcare related travel
Supervision /minding	11 (7%)	Active (non-healthcare related) supervision/monitoring of children (eg. children playing), passive childcare, being an adult presence for children to turn to in need
	156 (100%)	

7.4.1 Importance of activities

The majority of activities were rated extremely important (65%) or important (29%). No activities were rated *total waste of time* (Table 7.3).

Extremely important was applied to 13 emotional care activities (93%), 29 (83%) healthcare activities, 28 (67%) engagement activities, 28 (52%) physical (feeding, hygiene/dressing, toileting) and four (36%) supervision activities. The majority (n=21, 88%) of procedure or treatment related activities (eg, suctioning, preparing/administering medication, monitoring seizures) were rated extremely important.

7.4.2 Competence

Mothers rated themselves competent (average competence or above) undertaking almost all childcare activities (Table 3). This included performing 25 (46%) physical care activities, 10 (71%) emotional care activities, 21 (51%) engagement activities and 21 (60%) healthcare activities very well. The healthcare activities included 15/24 (63%) procedure or treatment related activities.

7.4.3 Enjoyment of activities

Sixty-nine (44%) activities were liked or strongly liked (Table 7.3). The only disliked emotional task was calming an extremely agitated child. The other 12 (86%) such activities were strongly liked. Ten (91%) of the disliked toileting and hygiene/dressing activities involved an older CCN (>4years) including bowel massage, changing a bed, toileting, cleaning teeth, showering.

Almost half (48%) of all disliked activities were healthcare activities. Enjoyed healthcare activities (n=5) included healthcare related communication and travel, walking with a child needing assistance and maintaining equipment. Thirteen (54%) procedure or treatment related healthcare activities were disliked or strongly disliked, none were enjoyed. Fifteen medication (oral, PEG, inhaled, topical) activities were neither liked nor disliked (n=9, 60%), the remainder disliked.

Table 7.3: Mothers' rating of their competence, value and enjoyment of childcare activities

	Competence			Value			Enjoyment		
Type of task	***Do well* or *Do very well***	***About average***	***Do poorly* or *Do very poorly***	***Extremely important* or *important***	***Take it or leave it***	***Rather not do it***	***Like it* or *like it very much***	***Neither like nor dislike***	***Dislike* or *Strongly dislike***
	N (%)	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
Emotional	14 (100)			14 (100)			13 (93)		1 (7)
Feeding	9 (90)	1 (10)		9 (90)	1 (10)		6 (60)	4 (40)	
Toileting	9 (82)	1 (9)	1 (9)	10 (91)		1 (9)		5 (45)	6 (55)
Hygiene/dressing	25 (76)	8 (24)		30 (91)	3 (9)		11 (33)	17 (52)	5 (15)
Engagement	30 (71)	11 (27)	1 (2%)	41 (98)	1 (2)		32 (76)	9 (22)	1 (2)
Healthcare	34 (97)	1 (3)		34 (97)		1 (3)	5 (14)	16 (46)	14 (40)
Supervision	7 (64)	4 (36)		9 (82)	1 (9)	1(9)	2 (18)	7 (64)	2 (18)
Totals	**128 (82%)**	**26 (17%)**	**2 (1%)**	**147 (94%)**	**6 (4%)**	**3 (2%)**	**69 (44%)**	**58 (37%)**	**29 (19%)**

N= number of activities

7.5 Discussion

Mothers in this study rated childcare related activities important and perceived themselves competent to undertake these activities, including healthcare related activities such as suctioning, monitoring seizures, pressure area care and physiotherapy. However, valuing a task does not mean it is enjoyed (Crowe, VanLeit, Berghmans, & Mann, 1997) and this was clearly displayed in the findings from this study. Of particular note is the mothers' dislike of performing healthcare related activities with/on their child.

Part of the role strain experienced by parents of CCN appears due to the dichotomy between being a parent and undertaking healthcare related activities (Whiting, 2014). Previous research suggests that watching healthcare procedures performed on their child hurts parents (Tong, Lowe, Sainsbury, & Craig, 2010) and that this is even more upsetting when the parent is the one doing the procedure (Sanders, et al., 2013; Swallow, et al., 2011). Parents of children with eczema dislike applying topical medications and causing pain or discomfort (Santer, et al., 2013) and parents of children dependent on technology describe themselves as more like a nurse than a mother (Kirk, Glendinning, & Callery, 2005). How well each parent copes with undertaking unpleasant activities is a factor in how some parents assign activities and share the home care of their child (Swallow, et al., 2011).

The mothers dislike of healthcare related activities does not appear related to competence, as the mothers rate themselves competent undertaking almost all childcare activities, including healthcare activities. This finding is supported by the literature, previous research suggesting that parents of CCN recognize their expertise in relation to their child's condition and care, but it takes time for this to develop (Judson, 2004; Whiting, 2014), the families passing through a number of learning stages while becoming competent (Swallow, Lambert, Clarke, Campbell, & Jacoby, 2008). Mothers of infants discharged from a neonatal unit gain confidence in their healthcare related competency as the infant grows and health improves (Murdoch & Franck, 2012). However, being competent does not equate to enjoyment.

Healthcare activities were not the only disliked activities. Similar to Cant (1994) the parents did not enjoy toileting activities. The dislike was mainly associated with toileting/hygiene activities with an older (>4years) CCN. The small numbers make it difficult to draw conclusions, but this finding supports difficulties expressed by parents when attending to hygiene/toileting needs as the child gets older and heavier (Murphy, Christian, Caplin, & Young, 2007; Steele & Davies, 2006). Nurses identify direct care activities such as positioning and assisting a patient with activities of daily living as the most physically fatiguing, particularly with larger or 'total care' patients (Steege, Drake, Olivas, & Mazza, 2015). Mothers were mainly neutral about supervising their child, although disliked managing a child with Autism Spectrum Disorder (ASD) in the supermarket and checking their CCN during the night.

The activities most enjoyed by mothers were those associated with nurturing their child such as cuddling, calming, reading, playing. This is not just common to mothers, fathers of children with ASD nominating morning rituals, play and shared time as periods they feel most like a father (Donaldson, Elder, Self, & Christie, 2011).

This pilot study has limitations. It included 156 activities from 10 mothers and may not represent the views of parents of CCN more generally. However, precedent exists for the use of this tool in even smaller (5-7 participants) sample sizes (Cahill, Connolly, & Stapleton, 2010; Niva & Skär, 2006). Strengthening the study is the wide range of activities that were included on the Occupational Questionnaire for each mother and the fact that mothers rated their own rather than general activities, a potential limitation of studies where parents rate or score activities on a checklist. Also, only mothers participated. Research selectively targeting fathers of CCN is required to identify whether they show similar patterns in the childcare activities they enjoy, value and feel competent undertaking.

7.6 Conclusion

Parental dislike of performing healthcare-related activities despite self-reporting high levels of competence is a key finding and worth further investigation. The fact that parents of CCN frequently perform activities they dislike clarifies the role tension described by parents, particularly in the context of the high enjoyment of emotional care activities. Paediatric nurses need to understand the impact this may have on the parents and their family relationships and find ways to support families so this care can continue to be provided.

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Chapter 8 - Home adaptations when living with a child with ASD

Chapter 8 contains a paper that will be submitted to a journal with a focus on ASD. The paper focuses on the strategies used by parents when living with a child with ASD, with an emphasis on home adaptation.

The study on which this paper is based arose out of shared interest with a colleague Dr Ceridwen Owen, who is an architect. Dr Owen had an interest in experiences of home and I was exploring home care of children with complex needs, both with experience in using self-directed photography as a data collection method. This study was the result of these common interests and was conducted in 2012 with funding from an internal cross disciplinary research grant at the University of Tasmania.

Both Dr Owen and I were equally involved in the study design, conduct and analysis. Two papers will be produced based on the study findings. I am the lead author on the one presented in this chapter and wrote the paper. Dr Owen has provided critical review of the paper and made suggestions on earlier drafts and is the second author. Dr Owen is the primary author on a second paper (I am second author) focused on the spatial and sensory aspects of home adaptation and modification when living with a child with ASD.

The autism and home study has generated interest locally, nationally and internationally. We have presented the findings to staff from the Department of Education in Tasmania, including autism consultants, have been interviewed on local ABC radio and had a story in the local paper *The Examiner*. The study also featured in the University of Tasmania *Research to Reality* publication (2012) that focuses on innovative research being undertaken by staff at the University of Tasmania.

We have recently been contacted by a representative from the National Disability Insurance Agency requesting information regarding the research we have undertaken in this area, in particular because of the lack of research relating to home modification

and the impact of the built design on people with ASD and intellectual disability. Reference to our work has been included in a recent submission prepared by that agency.

A full conference paper *Picturing home: self-directed photography as a lens to explore the home environment in the care of children with Autism Spectrum Disorder* was presented at the 7th Australasian Housing Researchers' Conference in 2013 and subsequently published (Appendix 5). This paper focused on the study methods and preliminary findings. Dr Owen was the lead author. An oral presentation of the study findings was delivered by myself and Dr Owen at the Asia-Pacific Autism Conference held in Brisbane, Australia in September 2015.

Submitted paper: Home adaptations when living with a child with Autism Spectrum Disorder: a photo-interview study

8.1 Abstract

Introduction

Limited information exists regarding home modifications required when living with a child with Autism Spectrum Disorder (ASD).

Methods

We conducted a photo-interview study with seven parents living with at least one child with ASD. The parents took photographs focused on adaptations to the home environment that formed the basis for a face-to-face interview. Framework analysis was used to analyse the data.

Results

A number of themes relating to the home adaptations and modifications were identified. This paper focuses on findings related to carer strategies (including home adaptations). Three key themes were identified: Keeping safe; Reducing anxiety; Picking battles.

Conclusion

Families adjusted and accommodated to meet the needs of all family members. In the case of the child with ASD, this included picking the battles worth fighting, adhering to routines, closely monitoring the child with ASD, altering family function, and modifying the structure and function of the home itself.

8.2 Introduction

Home care with parents as the primary caregiver is the contemporary model of care for children with complex needs (Ward, Glass, & Ford, 2014), the children thriving when cared for at home by a loving family (Bourke-Taylor, Pallant, Law, & Howie, 2013). However, living with a child with complex needs may significantly impact on the family and home environment, the needs of the child with complex needs assuming priority and the care of other children and family activities orchestrated around their high care demands and/or restrictions (Johnson et al., 2006; Koch & Mayes, 2012; Nicholl & Begley, 2012).

There is increasing awareness of the medicalisation of home that occurs when living with a child dependent on technology and the reduction of privacy and comfort due to the presence of healthcare professionals and care providers (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Heaton, Noyes, Sloper, & Shah, 2005; Kirk & Glendinning, 2004; Kirk, Glendinning, & Callery, 2005). Parents describe the need to adapt their home to accommodate supplies and meet the clinical and mobility needs of a child with complex needs (Carnevale et al., 2006; Swallow, Lambert, Santacroce, & Macfadyen, 2011). To date, much less attention has been paid to home adaptations required when the disability relates to cognitive impairment and the needs are highly idiosyncratic, as is the case for families living with a child with Autism Spectrum Disorder (ASD).

There is an emerging picture of the experience of living with at least one child with ASD. Previous research has described the ways families function following a diagnosis of ASD (De Grace, Hoffman, Hutson, & Kolobe, 2014), the construction of 'normal' family life (Gray, 1997) and how having a child with ASD affects family routines and activities (Larson, 2006; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Parents have described the negative impact on their privacy and/or disrupted domestic routines when therapists provide home-based applied behaviour analysis (ABA) programs, particularly when the teaching occurs in private spaces such as bedrooms (Grindle, Kovshoff, Hastings, & Remington, 2009). For some parents, the inability to foster a home environment that meets the needs of all family members due to the increasing severity

in behaviour of their child with ASD, and the threat this poses to the safety of others in the house, is the main trigger for making the decision to place their child in care (Corman, 2013).

Pengelly et al. (2009) interviewed three mothers living with a child with ASD who had an additional dedicated room (time out room or second living space) in their home. For these mothers, the additional room enabled the parents to set boundaries, keep an eye on their child, maintain control, deal with crisis points, and provide a safe space for siblings (Pengelly, Rogers, & Evans, 2009). But there remains very little research focused on the broader home environment in families living with a child with ASD (Pengelly et al., 2009) or more generally on the practices of caregivers interacting with their children at home (Boles & Roberts, 2008). The overall aims of this study therefore were to: 1) gain a better understanding of the modifications and adaptations occurring in the homes of families living with at least one child with ASD; and 2) to explore the relationship between this modification and adaptation to the home environment and practices of care in families living with a child with ASD.

8.3 Methods

This was a pilot study undertaken by researchers from the disciplines of nursing and architecture. The research employed the method of self-directed photography, where data is gathered through photographs taken by participants in combination with in-depth photo-interviews. The use of self-directed photography enables data to be collected at a time that is convenient for the participants, minimising intrusion in their lives (Warren, 2005), but happening in the reality of their experience (Wang & Burris, 1994). The photographs provide an accessible way to supplement interview data with observations in the families' natural environment, generating a clearer picture of family functioning, occupations and routines when a family member has ASD (Boyd, McCarty, & Sethi, 2014).

Self-directed photography has been used to explore the experiences of siblings and parents of children with ASD (Harte, 2008; Latta et al., 2014). Self-directed photography, researcher photography and videography have also been used in research exploring meanings of home (Owen, 2011), to supplement interview data regarding the home modification process (Aplin, de Jonge, & Gustafsson, 2013), and to record physical changes in the home environment in families providing home based palliative care (Williams, 2004). To our knowledge, no studies to date have used self-directed photography to explore home modifications in families living with a child with ASD.

8.3.1 Sample

Information about the study was distributed via local radio, carer support groups, an ASD specific school and a consultant working with families with a child with ASD. Parents living at home with at least one child aged up to 18 years who had been diagnosed with ASD were eligible for inclusion. Interested parents were given an information sheet and were invited to contact the researchers for more information.

8.3.2 Data collection

Parents interested in the study were sent a pack containing a digital camera and a journal to make notes about the photographs. They were asked to take photographs that focused on any modifications made to the home environment to accommodate living with a child with ASD. The camera containing the selected photographs and accompanying journal were posted back and a follow-up interview arranged. All interviews were conducted face to face by the two authors, in the home or a setting chosen by the participant. One was conducted via Skype to accommodate the participant's remote location. Hard copies of the photographs were brought to the interview and an in-depth dialogic interview about the meaning of each of the pictures (Berman, Ford-Gilboe, Moutrey, & Cekic, 2001) was undertaken.

8.3.3 Data analysis

Framework analysis (Ritchie & Spencer, 1994) was used to thematically analyse, code and categorise the data. Both researchers reviewed the journals and photographs prior

to each interview and made notes regarding key points of interest or emergent issues. All interviews were conducted by both researchers and the interview data transcribed verbatim. Both researchers read the transcripts to familiarise themselves with the material and identify recurrent themes (Ritchie & Spencer 1994). The initial thematic framework was based on *a priori* issues identified in published research and the emergent themes identified from the participant journals, the interviews and in the subsequent reading of the transcripts.

Indexing, the application of the initial thematic framework to the transcripts, journals and photographs, was undertaken using NVivo qualitative data analysis software by both researchers to ensure the cross disciplinary nature of the research was maintained. The initial thematic framework was refined following the indexing stage. Case charts were created in Excel spreadsheets to chart where data from participants corresponded with themes and sub categories. Direct quotes from participant journals and interviews were entered in the spreadsheet under relevant themes and sub categories with accompanying notes from the researcher if appropriate. These case charts enabled comparison across cases and were used to analyse the content and nature of each theme (Swallow, Lambert, Santacroce, & Macfadyen, 2011). The case charts and transcripts of the interviews and journals were then systematically examined to compare and contrast the individual cases, search for associations or connections between the identified themes and provide explanations (Ritchie & Spencer, 2002). Through this interpretive process, the themes and sub themes were further refined.

8.3.4 Ethical considerations

The project was approved by the Tasmanian Social Sciences Human Research Ethics Committee. The use of participant-generated photographs poses a specific challenge in relation to maintaining the confidentiality and privacy of the participants, particularly if the images are used when disseminating the findings (Balmer, Griffiths, & Dunn, 2015; Bugos et al., 2014). A number of ethical safeguards were therefore employed. The parents had complete control over which photographs were taken and used. A detailed consent form gave parents the opportunity to identify photographs that could be used for publications and presentations.

8.4 Results

Eight parents responded to the recruitment information and received further information and seven chose to participate in the study. The ages of the study children ranged from 7 to 18 years. Two children were described by their parent as having mild to moderate autism (participants F and G); two children were described as having high functioning autism (C) or Asperger's (A); and one child was described as having significant Asperger's (B). One child (H) was described as having mild autism and had an older sister with severe autism and an older brother with Asperger's. Another family (E) had two children with ASD, one described as having severe autism and the other high functioning Asperger's.

A number of themes relating to home adaptations and modifications used by parents living with a child with ASD were identified. This paper focuses on those specifically related to the carer strategies (including home adaptations) used by the parents. Three key themes were identified: *Keeping safe*; *Reducing anxiety*; and *Picking battles*.

8.4.1 Keeping safe

Every parent in the study spoke about the importance of keeping their child safe and described modifications and ways of living within the home environment to ensure the safety of both the child/children with ASD and other family members.

8.4.1.1 Being alert and monitoring

Parents spoke of the need to monitor what their child was doing at all times, *a 24 hour watch…alert the whole time the child's present* (Participant E). For some parents, this meant constant vigilance and the need to have the child always within sight and directly supervised:

> *You have to be aware of where she is all the time and what's she's doing. Because she can be doing something quite quietly…and you go and find she's actually gotten something and done something with it that you didn't want her to do* (H)

Auditory monitoring was also used, one parent describing how her son's love of cars enabled her to remain alert to what he was doing: *I just sit and listen for the brooming noise, and then I could identify where he was in the house* (C).

The need for direct supervision and vigilance was most clearly seen in families living with a child the parents identified as being on the severe end of the spectrum. For these families, the consequence of not constantly monitoring their child could just be a mess to be cleaned up: *Kitty litter all through the toilet, all over the floor* (E); *washing powder…she will tip it all over the floor and walk in it, and play in it, and rub it everywhere* (H).

Of much greater concern however, were instances when the child's life was literally placed in danger: *I have found myself running down the middle of the highway, into the oncoming traffic and I've had a semi-trailer pull up about four metres away from me and my daughter...that takes years off your life! (E).* The parents were acutely aware of how little time was needed for adverse events to occur: *you only have to have that window of opportunity where they can harm themselves, and they will harm themselves (H).*

Two parents placed less emphasis on the need to constantly monitor their child. For one child, his need to adhere to rules meant he *never does anything naughty. So, no, I completely trust him* (G). Another child would go and play in the park near home alone, although the parent *wouldn't have felt comfortable with him doing that only a year or so ago* (F). However, this parent did acknowledge that they had to supervise their child with ASD more than their other children.

8.4.1.2 Modifications to improve safety

Modifications to the home environment assisted the parents to keep their child safe. Gates and fences were an important means of preventing 'escaping', *that's why we've got a six foot fence around the house* (E). Enclosed backyards provided a safe environment benefitting parent and child: *she can run outside and jump on the*

trampoline, and swing on her swing, and you know she's safe, and you know she's happy, and she can't get out of the yard (H).

Parents made adaptations to the home to provide an additional layer of warning and protection, such as bells on windows to alert them to a child trying to get out of a window at night while they slept: *Backups like this are necessary because despite all our best intentions it is not possible to be vigilant 100% of the time* (E Journal entry)

8.4.1.3 Risk avoidance versus risk minimisation

Two distinct risk management approaches were used by parents to keep their child safe from potentially hazardous aspects of the home environment, demonstrated by how three parents managed the presence of a wood heater in the home. Two parents living with a child who they described as being at the severe end of the spectrum took a risk avoidance approach, restricting access to the wood heater by using screens and barriers: *We have a full wire gate across the front of the fire to prevent our daughter from touching any part of the hot fireplace* (H journal entry). *No easy option of a mere guard here – all out with a completely enclosed, bolted to the wall, locked unit – custom built* (E journal entry).

One parent had made a conscious decision to facilitate the ability to be aware of danger in their child by taking more of a risk minimisation approach, allowing access to the heater, but ensuring the child was supervised at all times when in the room: *we wouldn't leave him around the heater without us being, you know, actually within view of him* (F).

Participant E

Participant H

Participant F

This risk minimisation approach reflected the conscious decision by Participant F to expose their child to managed and supervised danger or potential hazards to develop the child's functional ability and level of independence. This included allowing their child to sleep in the top bunk despite his poor coordination and lack of risk awareness, or altering behaviours that may be harmful: *he had a thing where he would always want to grab the bees, and he would get stung …rather than, the initial thing was, "Don't go near them!" You know, I'll say, "Oh, let's go and have a look at them…but we don't touch them, do we?"* (F).

8.4.2 Picking battles

Parents described strategies that they used to negotiate with their child in order to achieve desired behaviours or discourage unwanted ones. A key feature was picking the battles to fight compared to times when parents conceded in order to make life easier for themselves, their child and the whole family. *You pick your battles. You learn…to discern what's very important and what's not important, you know…Safety and sanity, I guess!* (E).

> *And if the kids want to eat in this room, honestly, I'm not fussy. I'd rather just not stress and pay to get the couch cleaned, than stress over constantly eating at the table all the time. Because I've been like, fairly strict in the past about always eating at the table. But I've sort of got to the point where life's got to be a bit easier (A).*

8.4.2.1 Persistence versus impact

There was an acknowledged trade-off between persisting in encouraging or discouraging certain behaviours and the impact this had on the parents and family members. Some parents allowed behaviours or altered the functioning of their home because it simply took too much energy and time for them to fight the battle with their child. *I guess I've really come to the conclusion myself that there are some battles that I have to fight – like going to school – and it goes against the grain, but sleeping in the lounge is one that I've permitted* (B).

> *…some nights it'd be two or three hours trying to get her to sleep…. And we were just getting no time as a couple…And I said, 'Look. Just put a blanket over her, and she can go to sleep on the couch…I'm out of energy. Let's just do the easiest thing (A)*

The perceived importance of the behaviour or activity, coupled with the impact on the parents, family and home environment, all played a role in whether or not parents continued to battle with their child. Assisting the child to learn life skills and develop independence were key reasons given for choosing to persist: *sometimes it's a battle... it's really important for them to learn some of those skills* (G). But parents acknowledged the time and patience required to achieve these developmental milestones: *it took us eight years to teach our son how to spit when we brush his teeth* (E). *Reading is a good example….'Is it worthwhile trying to get this child to recognise these characters and put them together as words?' And he's a great reader now. But that's taken a lotta, lotta (sic) time over a period of years* (F).

Safety also played a key role in whether parents persisted in teaching their child about specific tasks or behaviours. *He's got no road sense, despite us trying to instil that in to him…I don't know how many times I've done that with him* (C). *I've had to enforce upon him that he has to tell me if he wants to go somewhere…I'm telling him about stranger danger, but how much he actually comprehends that…I just keep having to tell him* (F). But the same level of effort was not applied to teaching a child with ASD to ride a bike:

we tried when he was really young and it just seemed too difficult….So you don't do it, because it's just too hard. And we've got other children (F).

Dealing with the aftermath of behaviours that did not constitute a safety risk could be less difficult than preventing the behaviour occurring, even if that behaviour occurred daily:

On almost any given day our daughter devotes a lot of time to throwing things over the fence...Every afternoon we gather up boxes of items – toys, crockery, books, clothes (E journal entry).

8.4.2.2 Home and school

School attendance featured as a factor in whether parents chose to 'battle' with their child. Parents encouraged school attendance and ensured their child could meet the dress requirements: *I've put jean material next to him so that he could be like the other kids and wear jeans to college… just getting pants on him was nigh near impossible* (C). But this was balanced by a more relaxed approach in the home environment:

> *Because with her school uniform she's got to wear stockings, and school shoes, and you know she's got to have the right clothes on...But at home, if she doesn't want to wear clothes I just put a blanket over her. She's quite happy with that* (A)

While acknowledging the important role that school played in their child's development, parents at times adopted a different approach at home, despite this making home life a little more difficult: *…he does have that trait where visual prompts are easier. Again, although the school implemented them very well, and very successfully, we took a conscious decision not to do that sort of thing around the home* (F). One parent accepted that attending school for a full week was too difficult for their child, resulting in one day

of schooling occurring at home: *I never really thought that I would be in the position of home-schooling my child...I don't necessarily enjoy doing it. It's something that I have to do* (G).

8.4.2.3 Removing access

Two families removed access to aspects of home that encouraged unwanted behaviours rather than continually having to battle with their child: *anything that we want her not to have access to, we need to put away* (H). These parents struggled with removing access to appliances or features of their home that were easily accessible and prominently displayed such as plugs and switches. *The sorts of objects which most people have on display in their houses, knick knacks, family heirlooms, photos in frames, we are forced to keep under lock and key* (E journal entry).

> *Removing access to food was a particular concern: she's so obsessive about food that even if you throw it in the garbage bin she still will try and retrieve it. So we have the garbage bins inside the pantry too. They get locked away* (H).

> *Unless all food is either hidden or locked away we have no control over what, when and how much she eats…Next stage is to build a lock-up pantry for fridge, freezer and groceries* (E journal entry).

Removing access could also be employed as a temporary measure when the need arose:

…our daughter likes nothing better than to strip her bedding and drag the mattresses off. She will do this several times a day when the mood takes her so on these days we restrict access to the bedrooms – which causes temper tantrums. You have to pick your battles (E journal entry)

Family members lived with locked doors and restricted access to accommodate the child with ASD: *it's not like being in jail. I mean this house isn't like a jail, but it is a bit like, you have to be aware of it all the time* (H). *A master key would help to prevent one feeling like a jail keeper* (E journal entry). The parents also considered the possibility that they may need to remove access to other areas as the child grew or the needs of other family members changed: *…there may come a time, shortly, when we may have to lock his room off, so that he can have his own space…so that he's not being invaded by her* (H).

In some cases, removing access required significant modification to the home:

> *it didn't work for us having the laundry there, because it was right in the centre of everything, and it made it very difficult to keep [child] out of it…so my husband moved the whole laundry to the outer part of the house away from the main traffic area* (H).

8.4.3 Reducing anxiety

Reducing anxiety refers primarily to strategies and home adaptations parents used to reduce anxiety in their child, although these may also have been used to reduce parental anxiety.

8.4.3.1 Proximity/line of sight

Parents discussed the need to be able to monitor their child in order to continuously assess them and prevent them becoming upset or anxious: *I have insisted that he play in the living areas of the house so that I can keep some sort of eye on what is happening – mostly to monitor if he's becoming too upset with the games* (B journal entry).

Monitoring also occurred to reduce the impact on other family members:

> *…she'll get too close to him, or he'll get too close to her, and it's never quite right. And if she's just not feeling her best she'll lash out at him. And sometimes he'll just tease her. So I've got to be able to see them…she also needs to be able to see me* (A).

The function of rooms was rearranged to improve visibility and access, such as adjusting the positioning of lounge room and dining room relative to the kitchen to ensure the parent could maintain *line of sight* (A). In this family, the importance of being able to easily see the child from the kitchen was balanced against the child's poor tolerance of cooking noises, the background noise of the television an effective means of lessening the sensory impact of the kitchen sounds. For another parent, a large couch occupied a central place in the lounge room in close proximity to the computer equipment: *If [child] is cut off from his technological supports for any period of time he becomes very anxious – being on the couch allows him to calm down again* (B journal entry).

Having the parent visible or easily accessible was also used as a means of reducing anxiety: *she could see us all the time. And if she woke up we were there* (A). *I tell [child] that I'm going to the spare room and every 20 or 30 minutes he'll come down, just to make sure that I'm there* (B). The need to stay in close proximity placed limitations on some children's willingness to move around the home: *she has sort of played at the top of the stairs a little bit by herself. But yeah, on her own, unless we're there, she won't go up there* (A). Managing the need for proximity required some parents to be present for activities despite the child's functional ability: *I'd often have to go and sit in there with him…he'd get anxious, but he really did believe that when he was in the shower, the aliens would come and take the rest of us away* (G).

8.4.3.2 Outside spaces

Outside areas and play equipment, particularly trampolines and swings, assisted with managing a child's anxiety and stress levels: *He does love to be outside in the bush* (G). *Every afternoon when she comes home from school…she heads straight down and starts*

swinging. It used to be straight down and start jumping on the trampoline, you know, as a stress release, I guess, to just relieve that built up tension (E).

For one child, interacting with the family dog was a means of relieving stress and also provided opportunities for the child to develop a sense of responsibility:

he'll go outside, and that'll be a release for him…he could spend an hour or two just out there with the dog, just doing things with the dog, and talking to the dog (F).

8.4.3.3 Use of routines and aids

Parents used routines and visual aids to assist their child to function as independently as possible and to reduce the child's anxiety. Labelling was used to assist with tasks: *he likes order, but he has difficulty maintaining that order himself…So having labels is really important* (G). Visual aids were displayed in various locations around the home including the fridge *the central information receptacle* (B); a whiteboard *his wheelchair* (C); noticeboard (H); drawers in the child's bedroom (C) and windows (G).

Routines covered a range of activities and time points including the morning routine to help the child get ready for school, television viewing in the evening, and:

…menu options. This is something that he developed himself. And I think it just shows how much he relies on regularity and predictability. I mean we DO eat some other things [laughs] (B)

Interruption to established routines could generate anxiety in the child, even relatively simple alterations. Change from routine was possible, but for some parents, required preparation: *We can do change, but I have to let him know as far as possible, and then the day before, and then the hour before and he'll accept that, which is good* (B). Where possible, families tried to maintain routines outside of the home as well. A holiday was *fine if we're going somewhere we've been before…the same hotel, every time [laughs]* (B). Interrupting or changing routines, particularly outside of the home, could have a significant impact on the child:

> *…we take her to special café where you can get gluten-free food. But…when we got there the whole of the inside of the café had changed. The furniture had changed. The wall colour had changed. The food, it had all changed. And she went to pieces. Absolutely went to pieces because everything was different (H).*

One parent used a different strategy toward routines, choosing to deliberately upset the usual routine at times to teach their child how to cope with anxiety when things did not go to plan:

> *So sometimes we did purposely…forcefully change routines...It had to be in a controlled way. You couldn't just flippantly go and just leave him to it, because - particularly when he was younger - because he might not have dealt with it. But you had to be there to show him that it's OK and how we deal with it (F).*

8.5 Discussion

Three key themes summarise the carer strategies used by parents living with a child with ASD: *Keeping safe*; *Picking battles*; and *Reducing anxiety.* Straddling these themes is a picture of families adjusting and accommodating their family and home functioning to meet the needs of all family members, but particularly the child or children with ASD. The research demonstrates how strategies of care and family functioning are related to

the home environment and the extent to which the home is modified and adapted to support living with a child with ASD.

8.5.1 Keeping safe

Parents of children with ASD describe a need to constantly monitor their child, remaining vigilant inside the home and hypervigilant outside due to a reduced ability to control the environment (Schaaf et al., 2011). The study participants discussed the need to observe and monitor their child in order to keep the child safe, reduce the child's anxiety and lessen the impact the child may have on other family members. One mother described the need to be vigilant to observe and monitor her child with ASD, but also to protect the sibling. Siblings have described verbal and physical aggression directed at them from their sibling with disability, mostly children with ASD (Siblings Australia, 2012). Mothers describe the benefits of having additional space when living with a child with ASD, dedicated space assisting them to observe their child with ASD and provide the sibling with safe space (Pengelly et al., 2009). Designing the environment so that it facilitates rather than impedes the monitoring of children with ASD has also been employed to similar effect in a more formal care setting (Whitehurst, 2006) and in the care of individuals with Rett Syndrome (Danieli-Lahav & Lotan, 2009).

The combination of exceptional balance skills and lack of danger awareness (Talay-Ongan & Wood, 2000) means that some children with ASD are consummate 'escape artists', posing a significant risk to the safety of the child and causing stress to their parents. Parents of children with ASD have described the need to use locks within the home to keep their child and other family members safe (Schall, 2000). Two of the parents in this study used locks and bolts on windows and internal and external doors, balancing the inconvenience to themselves and other family members and the jail like appearance against the considerable abilities of their child. The vigilance required to prevent their child escaping remained just as constant overnight. Despite adaptations to the home environment to assist with vigilance, one parent described the need for one of them to be awake whenever their child was, echoing descriptions from previous research of the need for parents to sleep with one eye open (De Grace et al., 2014; Williams, Eilers, Heermann, & Smith, 2012). This highlights the impact that constant

vigilance has on parents who need to have their child's safety forefront of their mind at all times, even at rest.

For parents of children with ASD, home is a safer environment because it is known and understood and has been modified to meet the needs of the child (Larson, 2010). The parents in our study created this sense of safety at home in part through the use of home adaptations and modifications. Some of these modifications, such as the use of secure gates and fences and a guard around a wood heater, are common in families with a young child, both parental and environmental strategies used to reduce the risk of injury at home (Morrongiello, Ondejko, & Littlejohn, 2004). The difference for some families in our study was the need for these adaptations and modifications to persist and become more substantial as the age of the child increased due to problems accommodating the child's increased physical development and capabilities combined with their complete lack of danger awareness.

Home modifications designed by therapists frequently involve the addition of rails, improved lighting and bathroom modifications or improving useability and accessibility by removing barriers (Aplin et al., 2013; Fänge & Iwarsson, 2005). For a child with ASD, the modifications focus more on removing access, erecting barriers to keep the child safe and prevent them leaving the home environment, or adaptations in family functioning to assist in monitoring the child and reduce their anxiety. The need for constant vigilance described by parents in this study highlights the fact that not all environments can be modified to reduce risk and this is compounded when there are behaviours less amenable to change (Morrongiello, 2005).

8.5.2 Picking battles

'Picking your battles' is a common theme in the literature describing the experience of being the parent of a child with ASD (Glazzard & Overall, 2012; Larson, 2006; Marquenie, Rodger, Mangohig, & Cronin, 2011). Parents decide which activity justifies the effort and significant energy expenditure required to alter a daily routine, basing their decision on the need for the change and the child's readiness to acquire a new skill (Larson, 2006). Many families face the dilemma of finding a balance between forsaking family traditions

or rituals in order to minimise arguments and disruptions and make it through the day (Boyd et al., 2014).

This study clarifies the parameters parents place around the battles that they chose to fight and those that require too much effort or impact too greatly on other family members. Lack of sleep or sleep disruption, time constraints, allowing time for other children, and ensuring the safety of all family members are key factors in developing these parameters. Parents will persist in a battle hard to win, but with potentially important outcomes for child and family, such as going to school. They do not persist if the gain is less significant and the price paid by family members is high. Instead, they adapt the home environment to lessen the chance of the battle occurring by altering the function of a room or by removing access to an area or activity, even to the extent of locking off areas of the home, or by accepting the behaviour and its consequences.

The strategy of removing access is also seen in families living with children with other types of disabilities or conditions. Children with physical disabilities that impair their mobility may have restricted access to some areas of their home due to the design of the house (Heywood, 2005) but parents of an adolescent in a wheelchair may also deliberately exclude the child from some rooms to restrict damage caused to furniture and fittings or create personal space for the parent (Mayes, Cant, & Clemson, 2011). Parents of children with Prader-Willi syndrome use locks to restrict access to food despite associating the use of locks with an institutional setting, rather than a family home (Allen, 2011). Although many of the families worked toward a lock free environment, it was easier to deal with the inconvenience caused by the restricted access rather than the behavioural problems that arose if access to food was not controlled (Allen, 2011), reflecting the 'picking battles' approach described by parents in our study.

8.5.3 Reducing anxiety

Children and youth with ASD are at increased risk of having an anxiety disorder or being in the clinical range for anxiety (Joshi et al., 2010; Williams, Leader, Mannion, & Chen, 2015). The parents living with a child with ASD with co-occurring anxiety adapted their

home and the way the family functioned within it to reduce or manage the child's anxiety and assist them to function independently. Strategies included reorganisation of the home and activities to maintain access to technological supports and proximity to family members while simultaneously managing anxieties associated with sensory overload.

The creation of strategies and routines to accommodate living with a child with ASD and enable family activities to take place with as little disruption as possible is a common theme in research in this area (Larson, 2006; Schaaf et al., 2011), the needs of the child with ASD taking centre stage in the structuring of the routines (Bachraz & Grace, 2009; Marquenie et al., 2011). The family has to be flexible to accommodate the needs, anxiety and perhaps inflexibility of the child with ASD, but ironically, this flexibility may be demonstrated through the family's readiness to adopt routines both within and outside the home (Schaaf et al., 2011). Families adapt mealtime practices, the altered practices then becoming integrated into normal mealtime routines (Ausderau & Juarez, 2013). For one family in the current study, meeting the needs of one of their children with ASD necessitated a regimented approach to meals they maintained even when the child was not present. Routines are reinforced by modification to home including visual aids to support the child's autonomy in undertaking everyday tasks.

Deviations from routine often lead to anxiety for a child with ASD (Larson, 2006). Despite this, one of the families in our study adopted a deliberate but carefully controlled strategy of disrupting their child's routine in order to improve the child's coping skills. This approach has also been described by parents of children with Prader-Willi syndrome, although the experience of the child is balanced against the needs of other family members (Allen, 2011). In another approach, the provision of safe spaces within the home, particularly in relation to outdoor environments, offers mutual benefits in managing anxiety and stress levels for children while relieving the burden of continual vigilance and associated anxieties for carers.

8.5.4 Limitations

This was a pilot study based on a small sample size, although the number of participants is comparable to studies in this area (De Grace et al., 2014; Larson, 2006; Pengelly et al., 2009; Schaaf et al., 2011). Despite some commonality in the parent descriptions, even in this small sample there is wide diversity in the experiences, types of strategies used and home adaptations needed, reflecting the different needs and behaviours of the children. This reflects the diversity of children with ASD more generally and provides an interesting snapshot of the home situation for families living with a child with ASD. The findings from this study suggest that more extreme adaptations are required when living with a child with more severe behavioural needs, but adaptations to the home still occurs in families living with a child with lower care needs.

8.6 Conclusion

In most cases, the parents in this study normalised their family life despite adherence to routines or patterns of behaviour that altered the way the family functioned within the home. As one participant expressed it: *If you saw us at home, we'd just look like a mother and son. There haven't been real physical changes, but how we do things is very different now*. Families adjusted and accommodated to meet the needs of all family members. In the case of the child with ASD, this adjustment included picking the battles worth fighting, adhering to routines, close monitoring of the child with ASD and their interactions with others, alterations to the way the family functioned within the home and modifications to both the physical fabric of the home and the use of space within the home. Families sharing home life with a child with ASD navigate the child's journey with them. How well the family travels along that journey includes their ability to adapt the home environment and implement strategies that encourage and support the child with ASD while also considering the needs and wishes of other family members.

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Chapter 9 - Is the vigilance continuous partial attention?

Chapter 9 contains a paper published in *Child: Care, Health & Development*. The paper applies a concept previously only used in the context of information technology as an alternate way to explain the type of vigilance required by parents of children with complex needs. This theory arose from the research presented in Chapters 3-8 and the consistent theme of vigilance identified in these studies, particularly the research presented in chapters 3, 4, 6 and 8.

9.1 Publication specific details

Citation: McCann, D (2015, Aug 18). Does Continuous Partial Attention offer a new understanding of the required vigilance and associated stress for parents of children with complex needs? *Child: Care, Health & Development*. Advance online publication. doi:10.1111/cch.12275

Child: Care, Health & Development has an impact factor of 1.692 and is ranked 36/68 in Psychology Developmental and 49/119 in Paediatrics based on the 2014 Journal Citation Reports (Thomson Reuters, 2015)

9.2 Published paper: Does Continuous Partial Attention offer a new understanding of the required vigilance and associated stress for parents of children with complex needs?

Chapter 10 - Discussion and conclusions

You are constantly on duty 24 hours a day, seven days a week…Most intensive parenting duties decline as the child grows and matures, [but] this is not the case for a child with a severe disability. I will have to be on call 24/7 until the day I die.

(Carer Payment (child) Review Taskforce, 2007, p. 3)

The aim of the research program presented in this thesis was to make more visible the often invisible work undertaken by parents caring for a child with complex needs.

The individual research studies that comprise the research program have been presented in chapters 3-8. Each of these chapters is written as a complete paper that includes a discussion of the additional knowledge contributed by the study and how it fits within the current literature. It is therefore not the intention with this discussion chapter to rediscuss these findings at an individual study level. Instead, this chapter will summarise and integrate the key findings from the research program overall and discuss them in the context of the theory presented in Chapter 9. Particular emphasis will be placed on how the key findings contribute to improved understanding and to the development of more effective strategies for supporting and assisting parents caring for a child with complex needs.

10.1 Summary of key findings arising from the research program

There are a number of key findings and points of interest that arise out of the studies (Chapters 3-8) contained within the research program presented in this thesis:

- Parents of children with complex needs carry a significant caregiving burden based on the amount and intensity of the care they provide, and this care does not proportionately decrease as the age of the children increases.

- The intensity of the care results from the type of care that some children require, but also from the fact that parents frequently undertake two childcare related activities at the same time or combine childcare related activities with other activities such as domestic activities.

- The type of vigilance required by parents of children with complex needs requires a higher level of supervision or monitoring than is generally expected of parents and parents have very little opportunity to be relieved of this responsibility.

- More time is devoted to the care of children with complex needs than the care of other children in the family irrespective of the size of the family, with a possible exception being the presence of a younger child (aged less than 4 years) who does not have complex needs.

- Parents enjoy activities associated more with parenting rather than the caregiving role and actively dislike undertaking healthcare related activities with or for their child, despite acknowledging their competence in undertaking these tasks.

- Caring for a child with complex needs impacts on family relationships and the home environment.

These key findings highlight aspects of the parental caregiving role that have been relatively unknown or poorly understood to date, including: the types and combinations of activities undertaken by parents and how they feel about them; the type and amount of vigilance required by the parents; and the need for home modification and alterations to family functioning for a subgroup of parents of children with ASD. Taken together, these findings suggest that many parents of children with complex needs are operating at a level of intensity that may be unsustainable in the longer term. This caregiving affects not only the parents themselves, but also impacts on the family and the home environment. The remaining discussion in this chapter focuses on the intensity of the parental caregiving role and explores how best to support parents caring for a child with complex needs.

10.2 The intensity of parental caregiving

> *We are given the impression over and over again that this is our child, our responsibility; we just need to learn to live with it…we find ourselves in a place after 3 ½ years where we can no longer 'live with it'.* (Eerden, 2013, p. 3)

The intensity of the caregiving experience for parents of children with complex needs is apparent in the systematic reviews and time use study presented in Chapters 3, 4 and 6 and this is well supported through the descriptions and stories of parents captured in previous research in this area. The magnitude of the responsibility, the need to be constantly available to respond if and when required, the constant planning and preparation in an attempt to pre-empt situations that may negatively impact on their child, and the need for constant vigilance to prevent untoward events and keep their child safe are just some of the additional pressures, roles and responsibilities contributing to the intensity of the caregiving experience for parents of children with complex needs (Johnson et al., 2006; Larson & Miller-Bishoff, 2014; Morawska, Calam, & Fraser, 2015; Murdoch & Franck, 2012; Nicholl & Begley, 2012; Safe et al., 2012; Thomas, 2011; Whittemore et al., 2012).

Intensity has been described in one time use study as the lack of opportunity for parents to take a break, using as proxy measures the opportunities for uninterrupted leisure time, recorded interruptions of sleep and the longest periods of uninterrupted sleep (Thomas, 2011). In another study, intensity was measured by the number of different caring activities undertaken in any one day (Crettenden, 2008). Within the general population, the term 'intensive parenting' has been used to describe an increasingly child centred approach to parenting, the original focus on intensive mothering (Hays, 1996 cited in Henderson, Harmon & Newman, 2015) broadening to reflect the increased time spent with children by both fathers and mothers, including the increased involvement in childcare related activities by fathers (Craig, Powell & Smyth, 2014). In the general population context, 'intensive parenting' involves the parent constantly stimulating their child in order to optimise the child's intellectual, social and emotional outcomes, parents sacrificing personal care or child free time to maximise time spent with children (Craig, Powell & Smyth, 2014; Schiffrin et al 2015).

This form of intensive parenting has some commonalities with the intensity of the caregiving experience for parents of children with complex needs. Parents of a child with complex needs do undertake treatments, provide care and stimulate their child in order to maximise their child's developmental outcomes. They also sacrifice personal care and leisure time to spend time caring for their child. The key point of difference though, is the fact that parents of typically developing children to a large extent make choices in regard to the activities in which their child is involved and the time they spend in child related and family activities. Parents of children with complex needs largely have no other choice. For these parents, the intense parenting associated with caring for their child is directly related to the child's care needs, which may include complex healthcare related needs, and provided in the context of a child who remains fixed in a developmental stage, struggles to progress to the next developmental milestone or even regresses developmentally (Woodgate et al., 2015). The type and combinations of activities undertaken by the parents and the need for constant vigilance are also key factors in the intensity of the caregiving experience for parents of children with complex needs, differentiating their care experience from that of parents of typically developing children.

10.2.1 Simultaneous activities

Throughout this thesis, a clear picture has emerged of the ways in which mothers of children with complex needs combine activities and use specific strategies throughout the day in order to meet the needs of their child with complex needs, their other children, their family and the household. What is apparent from my time use study (Chapter 6) is that mothers of children with complex needs spend relatively little time in sole activities, particularly for themselves, and a considerable proportion of their time juggling the care needs of their child with complex needs and other children in the family. The childcare is also combined with domestic activities and leisure activities, reinforcing the notion that even when mothers are involved in a primary leisure activity, they are unable to completely switch off from their child caring and domestic responsibilities.

Secondary childcare has been described as passive childcare (Jones, 2008), but for the parents who participated in the studies in this research program, their secondary childcare requirements are often anything but passive. Entries in the time use diaries described secondary childcare that frequently requires active engagement from the parents, particularly for the mothers of children with ASD. Secondary childcare also included a substantial amount of the care for other children in the family while undertaking a primary activity, frequently care for a child with complex needs or a domestic activity. Child care activities that would generally be regarded as pleasant, for example bathing, playing or reading with children, may be less pleasant if the parent's attention is being simultaneously claimed by other responsibilities (Craig, 2006). This was frequently the case for the mothers participating in the time use study presented in Chapter 6.

10.2.2 Embedded care

In addition to undertaking simultaneous activities, parents of children with complex needs also incorporate therapy or treatment into other childcare related activities. Embedding or enfolding therapy and educational activities into a family's daily routines has been suggested as a way that health professionals can better support parents of children with complex needs and enable them to incorporate the additional care requirements into their already busy day (Crettenden, 2008; McConnell, Parakkal, Savage, & Rempel, 2015). Staff prescribing interventions or therapy for parents to undertake with their child at home frequently incorporate the therapeutic tasks into existing activities, such as adding strengthening activities as part of play or incorporating speech therapy into daily activities, in recognition of the parents' existing responsibilities and limited time (Leiter, 2004). Parents of children with disabilities find it difficult to fully implement prescribed activities/treatments if additional time has to be found in their day and are more likely to implement the required therapy if it is incorporated into other activities (McConnell et al., 2015).

But incorporating therapy activities into everyday experiences can change the meaning of these experiences for the parents, altering a play at the playground with a child into work (Meehan, 2005). Parents of children with ASD using Applied Behaviour Analysis (ABA) spend a considerable proportion of their interactions with their child doing training due to the intensive nature of the program (Valentine, 2010). The expectations of therapists, intensive nature of the therapies and difficulties accessing professional services requires the parents of children with ASD to assume a therapist role (Karst & Hecke, 2012; Safe et al., 2012). Despite this huge commitment from the parents, the evaluation of ASD therapies rarely considers the impact of the treatment on parents and families, instead being limited mainly to assessment of the child (Karst & Hecke, 2012).

There are therapeutic and family centred reasons for healthcare professionals embedding therapy and other care activities into everyday practices. Taking this approach has the potential to increase the amount of therapy occurring (thereby improving the development opportunities for the child) while not overburdening the

already time poor parents. Parents may themselves choose to embed care, fathers in one study incorporating rehabilitation into play and valuing the opportunity this presented for improving their child's development (Huang, Chen, & Tsai, 2012). While embedding care may be a logical way to deal with the time constraints of the parents and the high care needs of many children with complex needs, it adds a level of intensity to activities that otherwise might have provided an opportunity for parents to have some downtime and just enjoy their child. The exploration of mother's attitudes toward childcare related tasks described in Chapter 7 highlights the enjoyment that mothers gain from undertaking nurturing activities with their children and their dislike of healthcare related tasks and therapy. Health professionals need to remain conscious of the need for parents of children with complex needs to have a chance to just enjoy being a parent and be able to shed the therapist role, even for a short time.

10.2.3 Vigilance

Being available to a child, minding a child, generally monitoring the activities of children, or remaining in proximity to children as the responsible parent are all aspects of general parenting and is the type of supervision often classified as secondary or passive childcare in time use studies within the general population (Jones, 2008). Such categories have also been used in time use research with parents of children with complex needs (Brust et al., 1992; Crettenden, 2008; Crowe & Michael, 2011; Harris & McHale, 1989). But the level of supervision required to safeguard a child with complex needs, and in some cases protect others from the behaviour of the child is significantly different from the supervision required from parents of children who are normally developing (Goodwillie, 2014). It is this unique vigilance that is a constant requirement for many parents of children with complex needs and contributes substantially to the intensity of the caregiving experience.

The need for constant vigilance, or hypervigilance, and the requirements for parents to supervise and monitor their child with complex needs has been a consistent theme across the studies contained within this program of research. The need to supervise or monitor their child was identified as a particular time commitment for parents in the time use systematic review (Chapter 3), contributed significantly to the sleep

deprivation described by parents in the sleep systematic review (Chapter 4), was clearly evident in the time use study (Chapter 6) and was a significant factor in the parental strategies and home adaptations used by parents living with a child with ASD (Chapter 8).

These findings are well supported in the descriptions and stories of parents of children with complex needs that appear in the literature, particularly research exploring the experiences of these parents. Parents describe the amount and intensity of the vigilance that they are required to undertake in order to ensure their child remains safe and to monitor their child's condition (Larson & Miller-Bishoff, 2014; National People with Disabilities and Carer Council, 2009; Nicholl & Begley, 2012; Welsh, Dyer, Evans, & Fereday, 2014). But to date there has been limited effort to measure and quantify this vigilance in order to accurately capture whether and how much this vigilance contributes to the intensity of the caregiving experience. Only six of the 32 studies included in the daily time use systematic review (Chapter 3) included a category focused on supervision or minding. Monitoring or supervising was included in three of the seven studies that calculated daily time use included in the update of the systematic review (Chapter 3), but not as a separate category. The substantial time requirement in the studies included in the systematic review that did include supervision or monitoring as a separate category demonstrates the need for this aspect of parental childcare to be acknowledged and supported, particularly considering the impact that monitoring a child overnight has on the length and quality of parental sleep (McCann et al., 2015; Thomas, 2011).

When the supervision or minding is acknowledged and measured in time use studies, it more frequently appears as a secondary activity. This is despite the fact that even in the general population, the direct activities that parents undertake in caring for a child take far less time than the responsibility for overseeing the child (Budig & Folbre, 2004). Mullan & Craig (2009) argue that specific child care activities such as bathing or reading to a child are nested within the continual need for carers to create a safe environment for children, monitor their needs and intervene as required. This need to provide a

protective environment is the parents' top priority and provides the framework that governs how parents structure their time (Mullan & Craig, 2009).

This is very relevant in the care of children with complex needs and was clearly evident in the insights into the home environment of families living with a child with ASD provided through the photo-interview study (Chapter 8). The need for constant vigilance was a key factor governing some of the strategies adopted by the parents at home, including modifications to the home environment to assist in keeping their child safe. This was particularly evident in two of the families who were living with a child who the parents described as having severe autism. These families lived with the constant threat of their child being harmed, either at home or because the child 'escaped' from the safety of the home. For these parents, constant vigilance was quite simply a way of life. They could never let down their guard and the sense of heightened awareness remained overnight despite home modifications intended to provide a second layer of warning and protection so the parents could try and get some sleep.

Vigilance is the key focus in a number of published studies (see for example Goodwillie, 2014; Larson, 2010; Lee & Lau, 2012; Sullivan-Bolyai et al., 2003). The heightened sense of awareness and the need for constant vigilance (hypervigilance) is frequently described by parents of children dependent on technology (see for example Carnevale et al., 2006; Kirk & Glendinning, 2004; McNamara, Dickinson, & Byrnes, 2009; Nicholl, 2015). It is also apparent in the descriptions of parents of children with ASD (see for example Ryan, 2010; Safe et al., 2012; Woodgate et al., 2008). Vigilance is required to monitor a child's condition, keep the child safe and to anticipate potential problems and intervene before they happen (Lester & Reid, 2007; Thomas, 2011). Despite the increasing focus, the intensity of the vigilance and the impact on parents and family members living with a child with complex needs remains poorly acknowledged and understood.

Continuing to try and measure caregiver burden by measuring the time use of parents of children with complex needs fails to accurately portray what is really occurring in the lives of these parents because the intensity of the caregiving experience is so poorly captured. Chapters 6 and 7 provide a previously unavailable level of detail regarding the activities parents undertake when caring for a child with complex needs, how these activities are combined, and the level of enjoyment and value parents assign to childcare related activities. This information improves our understanding regarding the intensity of the caregiving experience. The amount of time parents spend in active or passive supervision is more clearly documented than the majority of previous time use research in this area, but the level and intensity of the vigilance required by the parents is still poorly captured and measured, despite the level of detail supplied.

Taking the concept of continuous partial attention and applying it to the care of children with complex needs (the theory presented in Chapter 9) is an attempt to better explain what is occurring for parents remaining constantly vigilant to the needs of their child. However, while this theory contributes a new way of thinking about the care of children with complex needs and therefore an improved understanding, even the 'always on' mentality associated with continuous partial attention perhaps fails to truly capture the unsustainable level of intensity and vigilance (hypervigilance) required by these parents.

No data collection tool was located that has quantitatively measured the type and amount of vigilance required by parents of children with complex needs. This lack of measurement makes it difficult to convey the impact of the vigilance on the parents and therefore justify the need for support for these parents, exacerbating the invisibility that many describe. The most promising approach may come from child safety and injury studies. In research in this area, supervision is defined as:

> *…behaviours that index attention (watching and listening) in interaction with those that reflect state of readiness to intervene (touching/within arm's reach/beyond arm's reach), with both types of behaviours judged over time to index continuity in attention and proximity (constant/intermittent/not at all).*
>
> (Morrongiello, 2005, p. 538)

This resonates strongly with the type of vigilance required by parents of children with complex needs, who frequently need to remain in close contact and proximity to their child and maintain constant attention.

Various approaches have been used in child safety research to try and measure the supervision that is occurring and the impact on child injury rates. Self report measures, observational methods and questionnaires have all been used to measure types of supervision, supervisory behaviours, children's risk behaviours and parental management of risk amongst others (Morrongiello, 2005). The Parent Supervision Attributes Profile Questionnaire (PSAPQ) (Morrongiello & House, 2004) is a tool that measures and relates caregiver supervision style to child injury risk (Morrongiello, 2005). This is not necessarily the approach needed for research into the supervision required by parents of children with complex needs. But it may provide a starting point and suggested direction for the development of a tool to measure the type and amount of supervision undertaken by parents of children with complex needs and enable an exploration of the reasons for why this supervision is required.

Morrongiello (2005) argues that supervision must be understood in the context of all the strategies caregivers use when managing child injury risk, and that this includes modifications to the environment, although unobtrusively observing in the home can be difficult. This highlights the value of the information gained through the photo-interview study with parents living with a child with ASD (Chapter 8). The use of photo-interviews enabled insights into the homes of these families without the need for physical intrusion into their private space. The result has yielded substantial information about strategies that parents use to protect their child and other family members, and how they adapt the home to facilitate this protection and as a means of reducing or managing the supervisory burden. A combination of a questionnaire, coupled with some form of observational approach, may provide a means for better understanding the type and amount of supervision that is occurring for parents of children with complex needs and how they feel about it in future research. The information gained from the photo-interview study in Chapter 8 provides a starting point for this work by suggesting some

of the parameters parents of children with ASD use when developing strategies and adapting their home.

There are no easy answers, but further research is needed and this research needs to benefit from research in related areas like child safety in order to better approach the issue of vigilance in parents of children with complex needs. Measurement is needed, if for no other reason than to enable parents to receive the support they require to maintain the at times extreme levels of supervision required due to their child's needs. At the very least, viewing the vigilance through the lens of continuous partial attention helps to explain the constant nature of the vigilance and assists with understanding the toll this hypervigilance may take on the parents and wider family and particularly the impact on the parents' health.

10.2.4 Impact of intensive caring on parents health

A primary reason for wanting to gain a better understanding of the intensity of the caring provided by parents, particularly the requirement for constant vigilance, is the impact of intensive caring on parents' health. Parents of children with complex needs experience poorer health (emotional, physical and psychological) compared to the general population of parents (Brehaut et al., 2004; Crettenden, 2008; Murphy et al., 2007; Raina et al., 2005). Approximately half of all children with a disability in a large UK national sample lived with a parent with a disability (Blackburn et al., 2010). While it is not possible to ascertain whether a percentage of this disability burden can be directly attributed to caring for a child with complex needs, the physical and psychological strain associated with being a parental caregiver is well documented.

The high demands placed on parents who have a child with ASD affects their physiological health and leads to mental fatigue and an increase in mental health concerns (Ekas, Lickenbrock, & Whitman, 2010; Karst & Hecke, 2012). There is an increasing focus on the stress associated with parenting a child with ASD, with high or clinically elevated stress levels reported in the majority of parents across a number of recently published studies in this area (Dykens et al., 2014; Epstein et al., 2008; Smith et al., 2010). Significantly higher stress levels have been reported in parents of children

with chronic conditions or illness, intellectual disabilities, developmental disabilities and technology dependence (Cousino & Hazen, 2013; Hullmann et al., 2010; Lee, 2013).

While the higher stress levels and resulting mental health impacts in parents of children with complex needs are of concern, there is increasing interest in how the chronic stress experienced by caregivers impacts on their overall health more widely. While an acute response to stress, the 'flight or fright' response, can have positive effects such as boosting cognitive productivity, chronic stress has a negative impact on physical health, primarily affecting the cardiovascular, immune and gastrointestinal systems and is linked to poorer mental health (Dykens & Lambert, 2013; Miodrag & Hodapp, 2010).

Chronic stress experienced by caregivers has been associated with increased systemic inflammation and dysregulation of inflammatory control (Rohleder et al 2009). Elevated systemic concentrations of C-reactive protein, a pro-inflammatory biomarker, have been reported in parents of children with ASD or ADHD, potentially placing them at greater risk of cardiovascular and other diseases (Lovell, Moss, & Wetherell, 2012). Hypocortisolism associated with exposure to chronic stress has been identified in more than 60% of mothers of children with developmental disabilities, particularly in mothers of children with ASD (Dykens and Lambert 2013).

High levels of chronic psychological stress has been linked to higher oxidative stress, lower telomerase activity and telomere shortening (equivalent to 9-17 years of additional cellular ageing) in mothers of children with chronic illness, with suggestion of a causal link between the caregiving stress and the telomere shortening (Epel et al., 2004). In a recently published study, caregivers of children with disabilities with higher perceived stress were 2.13 times more likely to have shorter salivary telomere length compared to a similar population of parents with lower perceived stress (Chen et al., 2015). These studies suggest that the telomere shortening in the parental caregiver population is linked to chronic stress rather than just the natural process of telomere shortening associated with ageing. Further research is needed to confirm whether the telomere shortening increases the risk of cardiovascular disease in the caregivers (Starkweather et al., 2014). These findings raise concerns for the caregivers as

individuals, but also constitute a significant public health concern (Miodrag & Hodapp, 2010).

Global stress rather than the act of caregiving contributed to a reduction in health related quality of life for caregivers in one study, this association occurring over and above the effect of caregiving strain (Litzelman et al., 2014). Higher levels of daily stress for primary caregivers is positively associated with the intensity of caring, but it is the difficulty of being able to fit in responsibilities that is particularly stressful for parents, not necessarily the total time that they spend caring (Crettenden, 2008). Findings such as these suggest that while acknowledging the physical strain that can accompany caregiving, it is not necessarily the tasks associated with caring for a child with complex needs that impact on the health of parent caregivers, but rather the stress associated with the intensity of the caregiving role.

The suggestion that continuous partial attention is associated with stress is one of the factors that resonates most strongly with the care of children with complex needs. Concerns about the potential negative health impacts resulting from the stress associated with paying continuous partial attention to mobile devices and technology is a key reason for recommendations to regularly switch off from these devices as a way to reduce stress (Stone, 2014). But children with complex needs do not have an off switch, making it difficult for parents to disengage from their vigilant caring role. Compounding this is the fact that the stress associated with the intense caring and vigilance is not balanced by the parents undertaking activities for themselves that assist in reducing stress or allowing the body to revitalise.

The rejuvenation that occurs with a restful night sleep better prepares a person to adaptively manage their stress (Leggett, Burgard, & Zivin, 2015). But the findings from the systematic review presented in chapter 4 highlight the sleep deprivation experienced by parents, in large part due to a need to monitor their child overnight and be alert to their needs. Interruptions to sleep were also described by the mothers in the time use study (Chapter 6). The need to keep their child with ASD safe was a primary reason for the interruptions to sleep described by parents in the photo-interview study

(Chapter 8). Compounding the lack of sleep is the reduced involvement of parents of children with complex needs in leisure activities compared to the general population of parents (see for example Crettenden, 2008; Sawyer et al., 2010; Thomas, 2011). In a study by Bourke-Taylor et al. (2013), there was an association between healthy sleep patterns and higher participation in health promoting activities, such as socialising, being physically active and spending more time in recreation in a group of mothers of children with complex needs. It is not possible to determine from this research whether having better sleep patterns encouraged health promoting behaviour or vice versa, but the association clearly warrants further investigation (Bourke-Taylor et al., 2013).

Reduced time spent in leisure activities is a double negative for the parents. Less time spent in leisure activities reduces the time the parents spend in exercise and activities that improve health, but also denies the parents the respite and escape from stress that is associated with leisure activities (Ruiz-Robledillo & Moya-Albiol, 2015). Based on the findings from the time use study (Chapter 6) the time that mothers do spend in leisure and personal care activities is frequently combined with childcare or domestic activities, thus denying the mothers the opportunity to properly switch off even when supposedly undertaking activities for themselves. The high level of engagement as a secondary childcare related activity required by the mothers of children with ASD described in both the time use (Chapter 6) and photo-interview (Chapter 8) studies adds weight to this. And it is findings such as these that reinforce the concept that the vigilance required by parents of children with complex needs (the continuous partial attention) is a key source of the high stress levels and associated physiological responses identified in research with subgroups of parents of children with complex needs, particularly parents of children with ASD.

So what can be done to reduce the intensity of the caregiving and the requirement to be constantly vigilant, decrease the associated stress, and encourage parents to take time for themselves and engage in activities that improve their physical, psychological and emotional health? The second part of this chapter discusses ways to better support parents caring for a child with complex needs.

10.3 Supporting caregivers of children with complex needs

There remains a need for considerably more research into the type and severity of health complaints experienced by parents of children with complex needs (Miodrag & Hodapp, 2010). What is apparent from studies to date, however, is that parents of children with complex needs experience poorer health and are at increased risk for poorer health in later life as a direct result of the stress associated with their caregiving role. Clearly then, supporting parents in a manner that reduces their stress, provides opportunities for positive experiences and reduces the intensity of their care requirements should be a key focus for health professionals and others supporting these parents and families. Providing a break from the caregiving role through respite, assisting parents to reinforce and celebrate the positive aspects of their caring role, and making the caring role more visible to enable better recognition of the parent support requirements are key areas of focus addressed in this section.

10.3.1 Respite care

> *When he is being cared for by someone else, I miss him, and when he is with me, I find that I cannot cope.* (O'Connell et al., 2013, p. 378)

The stress associated with the 'always on, anywhere, anytime' hypervigilance that characterises continuous partial attention is relieved by switching off from the source of the stress (Stone, 2014). This is difficult for parents of children with complex needs, particularly when the child's care needs or behaviour are complex or challenging and therefore outside of the scope of most family, friends and usual care providers (Carnevale et al., 2006; Lester & Reid, 2007; National People with Disabilities and Carer Council, 2009). It may become increasingly difficult for family and friends to share the care as the child gets older and the care needs evolve from a 'big baby that needed a lot of medicine' into the care of a child with more complex needs, who is much larger and no longer mobile (Yantzi et al., 2007 p. 50). Providing a break for the parents can therefore only happen if the care of the child is provided by someone whom the parents are confident can safely care for their child (McNamara et al., 2009; Welsh et al., 2014;

Yantzi et al., 2007). Access to formal respite services is one means by which this can occur.

There is not a clear definition of respite, the service varying according to the intended purpose, the location of the service, duration and the provider (Evans, 2013). In the context of children with complex needs, respite is generally seen as temporary care or the provision of short breaks that provide relief to the carers, opportunities for participation and development in the child, and promote and sustain family wellness (Dyches et al., 2015; McConkey, Gent, & Scowcroft, 2011; Thurgate, 2004). The respite care can range from a child-minding service by non-professionals through to full support and nursing care provided by registered nurses (Eaton, 2008).

Difficulties can exist in providing respite, particularly to children with more complex needs. Parents find it difficult to relinquish control to respite carers, first needing to establish a relationship of trust and confidence (Eaton, 2008; Macdonald & Callery, 2008; Welsh et al., 2014). One barrier to parents being able to place their trust in others caring for their child is the lack of competent and available respite care providers (Murphy et al., 2007). Depending on the severity of the child's condition and their care needs, family members may be regularly performing treatments and procedures that may be outside the knowledge and expertise of even healthcare professionals such as community nurses (Glendinning & Kirk, 2000; Samuelson et al., 2015).

This poses a challenge when trying to organise nursing or respite care, particularly in rural or regional areas removed from tertiary paediatric healthcare services like Tasmania. In a sample of 133 Dutch families, the children most likely to receive respite care were those who were not tube fed, did not have reflux and rarely visited a specialist (Tadema & Vlaskamp, 2010), arguably the children with the less severe conditions or with lower care needs. This may be related to the level of training of the staff. As little as four years ago, one of the main providers of out-of-home respite in Tasmania were unable to accept children requiring gastrostomy feeds or Schedule 8 medications because the staff were not trained to undertake these tasks, therefore limiting the opportunities for respite for families with children requiring this care (Doyle 2011,

personal communication). These limitations in the provision of respite are particularly problematic when considering the types of activities the mothers enjoyed and valued in the pilot study presented in Chapter 7. The mothers actively disliked performing healthcare related activities on their child, despite reporting high levels of competence. Providing a respite service that is able to relieve parents of this treatment role at least some of the time may provide the parents with better capacity to continue providing what can be complex and challenging care in the longer term.

Parents describe losing respite services because their child's behaviour deteriorates and becomes more severe and unmanageable (Corman, 2013). Thus at a time when parents require more support, the availability of respite decreases. The challenging behaviours described by parents of children with ASD in the photo-interview study (Chapter 8) highlights the intense nature of the care required if a child is to be safely cared for within or outside the home environment by respite service providers. However, research on the most effective models of respite care for children with developmental disabilities and severe behaviour problems is limited (Strunk, 2010). Service models that do exist are highly intricate, individually focused, and require highly trained and committed staff to provide respite services to children with severely challenging behaviour (McConkey et al., 2011). This is an area that warrants further research, particularly in the context of the increasing prevalence of ASD (Fombonne, 2009). In Australia, the increasing prevalence of ASD and developmental disabilities are a factor in the increased cost of the National Disability Insurance Scheme (NDIS) (Conifer, 2015).

Respite may not always mean completely removing the parent from the child's presence; Wray & Wray (2004) arguing that respite can be provided by simply moving the parent away from the frontline into more of a standby role. Cant (1994) describes parents of children with cerebral palsy and spina bifida as being conscious of both time and territory constraints as a result of their caregiving role. Having 'time to myself' within the home because the child is in the care of a family member, friends or at school may not represent leisure time, but it does mean that the parent can complete the required home tasks at the rate and in the location of their choosing, rather than being tied to a particular section of the house due to the needs of their child (Cant, 1994).

Parents in the time use (Chapter 6) and photo-interview (Chapter 8) studies described the additional time and planning required and the constant interruptions that can accompany undertaking activities with or in the presence of a child with ASD. Diary entries and interview data from the mother of a child with Rett syndrome and comorbidities in the time use study demonstrated how having a carer in the home for a few hours in the evening enabled the mother to devote more attention to her other children, but still be available to assist the carer as required.

One of the potential disadvantages of in home respite is the fact that it does not provide the parent with the opportunity to completely switch off from caregiving. Parents assist the respite carer due to a lack of confidence in their knowledge and skills or because the policies of the service provider impose restrictions on what the carer is able to do (Welsh et al., 2014). The parents also have to accommodate having non family members in their home (Coad et al., 2015; McNamara et al., 2009; Welsh et al., 2014). Having someone in the home overnight to care for their child means the parent may not need to be physically present and provide care to their child, but does not necessarily mean that the parent sleeps through the night. Sleep disturbance still occurs, the parents aware of their child overnight even when someone else is providing the care (MacDonald, 1995; Nicholl & Begley, 2012). However, there is potential for in-home respite to provide the parent with the freedom to undertake activities for themselves or other members of the family. In-home respite may not enable parents to completely turn off, but it at least may assist them to turn down their level of vigilance, although this is less likely to occur if the parent lacks confidence in the competency of the person caring for their child.

The descriptions of parents in the photo-interview study (Chapter 8) highlight the planning and need for adherence to routine that are often required when taking a child with ASD out of their familiar home environment. Having the child cared for at home by a familiar and suitably trained carer could provide the parent with opportunities to engage in other opportunities at home or elsewhere, even just to go to the supermarket, an activity used as an example by a mother in the time use study to illustrate why everyday tasks are more time consuming when undertaken with her child with ASD. For single mothers of children with ASD, respite time is spent predominantly running

errands, working or doing household related activities with limited time for relaxation (Dyches et al., 2015). However, having an opportunity to undertake errands or other activities without needing to simultaneously care for a child with complex needs makes mundane tasks easier for parents and perhaps more enjoyable. One potential loss associated with in-home respite is the lack of opportunity for the child with complex needs to socialise, experience new situations and learn new skills, benefits that are valued by both parents and children (Welsh et al., 2014).

Parents often use respite time to care for other family members, including spending time with other children, rather than in leisure or personal care activities for themselves (McConkey et al., 2011; Murphy et al., 2007). The siblings of a child with complex needs may receive less time and attention from their parents due to the high care requirements of their brother or sister (Fletcher et al., 2012; Gibson, 2014; Knecht et al., 2015; Koch & Mayes, 2012). Increasing the time that parents are able to spend with other children in the family may therefore benefit those children, their parents, and their relationship. This may be particularly the case in families where the care of other children is more likely to be undertaken as a secondary activity because the majority of the primary childcare related time is spent with the child with complex needs (see the time use study in Chapter 6).

Reducing parental stress levels is clearly beneficial when placed in the context of the links between chronic stress and poorer general health in parents of children with complex needs. However, the reduced stress and increased positive uplifts associated with respite for parents have the potential to have a much wider impact on the families of children with complex needs and the community. Evaluation of an Australian respite support program for carers of children with severe or profound disability concluded that the program, although seriously underfunded and unable to fully meet the respite needs of the target group, did reduce carer stress and enable carers to maintain and strengthen relationships with family and friends (Department of Families, 2011). Of interest is the fact that one third of the random sample of 1000 carers surveyed for this evaluation were carers of a child with ASD, highlighting their need for respite to decrease the stress associated with the intense caregiving and hypervigilance described

by parents in the time use study (Chapter 6) and photo-interview study (Chapter 8) and frequently described in the literature.

Although caution needs to be exercised in interpreting the findings due to the largely cross sectional data and difficulties with sample selection, research suggests that children with chronic conditions and/or disabilities, particularly intellectual disabilities are at higher risk of suffering abuse than the general population of children (Horner-Johnson & Drum, 2006; Sullivan & Knutson, 2000; Svensson, Bornehag, & Janson, 2011). Single parenting, emotional strain, exhaustion and a reluctance to discuss abuse with professionals have been identified as contributing factors (Rodriguez & Murphy, 1997; Svensson, Eriksson, & Janson, 2013). Providing respite may decrease the risk of child abuse, but further research is needed (Strunk, 2010). Placing a child in out of home care generally indicates that parents have reached crisis point (Eerden, 2013; Together for Disabled Children, 2011). The loss of respite services can be a catalyst for parents making this decision (Corman, 2013). Conversely, providing a respite service that meets the needs of families of children with complex needs in crisis reduces the demand for out of home care, resulting in significant cost savings to the community and assisting families to better cope with challenging behaviours of the child with complex needs and stay together, increasing the quality of life for the child, their parents and siblings (Together for Disabled Children, 2011).

Respite breaks do not in themselves develop skills or strategies in parents that will assist them to promote their own health (Dykens, 2015). Finding a way to develop or improve the parents' own skills and strategies in combination with respite care may provide the most effective way of supporting these parents and families.

10.3.2 Emphasising positives and building on strengths

Any successes, even small achievements, by a child with complex needs are celebrated, the parents experiencing pride and joy and experiencing positive uplifts when seeing the progress their child makes as a result of their efforts (O'Connell et al., 2013; Thomas, 2011). While onerous, the act of participating in the time use study (Chapter 6) provided one mother with an opportunity to celebrate her son's achievements and appreciate

the progress that had been made. The mother described watching her child with ASD playing outside and realising that he would not have played in that manner even a relatively short time before, his progress reinforcing that the efforts by family members (and the child) were yielding results.

Parents of children with complex needs often highlight the positive attributes that their child brings to the family and try to focus on these positives, the bright side of caring (Broberg, 2011; Lester & Reid, 2007; O'Connell et al., 2013; Thomas, 2011). Interventions and support programs can assist parents to find this focus. Shilling et al. (2015) reported a number of benefits resulting from the provision of a peer support program for parents of children with disabilities, including the befriended parents developing greater confidence and ability to cope with their emotional highs and lows, while the parents providing the peer support reported increased confidence, self-worth and the positive feelings gained from helping another parent, despite the emotional drain of befriending.

An increase of one hour per week of respite for parents of children with ASD increases positive uplifts while reducing parental stress (Harper et al., 2013). In a later study with single mothers of children with ASD, respite care did not reduce daily stress, but did increase the uplifts (positive perceptions of daily events) experienced by the mothers (Dyches et al., 2015). These positive or pleasurable experiences (the uplifts) can have health benefits; mothers who had more daily uplifts reporting fewer symptoms of depression, significant when considering that more than three quarters of the study sample were at risk of clinical depression (Dyches et al., 2015). Interventions that reinforce positive feelings by focusing on benefit finding (Ouseph, Croy, Natvig, Simoneau, & Laudenslager, 2014) in addition to the provision of respite services, may assist the parents to better cope with the stress of their 'always on' caregiving role.

There is no one size fits all intervention that will aid and support all families. For some parents there is little progress or even a deterioration in their child's condition over time. Repeating the same tasks over and over with no end in sight adds to the mental weariness of mothers of children with an acquired brain injury when there is no

detectable improvement in their child's condition (Jordan & Linden, 2013). A parent's sense of loss may become more painful rather than ease as they witness the children of family and friends achieving milestones that their child will never achieve (Babb, 2007; Carnevale et al., 2006). For these parents, there is no escape from constant bereavement and the never ending worry about their child (O'Connell et al., 2013) and finding positives may be more difficult.

While it may not be possible for health professionals to remove the stressors faced by families living with a child with complex needs, improving the coping skills and strategies of parents and focusing on family resilience may also assist families to better manage the stress (Kuhaneck, Madonna, Novak, & Pearson, 2015). Mindfulness-Based Stress Reduction (MBSR) is one approach that has been used successfully with parents of children with complex needs. Dykens et al. (2014) combined MBSR with positive psychology practice interventions with mothers of children with ASD or other disabilities. Neece (2014) used a MBSR program with parents of children with developmental delays, mostly autism. Both studies reported significant reductions in parental stress and depression, as well as reduction in parental anxiety (Dykens et al., 2014) and improved parental life satisfaction and fewer child behavioural problems (Neece, 2014). The use of a randomly allocated control group in both studies strengthened the study findings.

An individual cognitive and behavioural stress management intervention with caregivers of adult haematopoietic stem cell transplant patients was associated with a decline in perceived stress and less use of mental health services (Ouseph et al., 2014). Ruiz-Robledillo and Moya-Albiol (2015) encouraged leisure activities and emotion regulation strategies using cognitive-behavioural techniques aimed at assisting caregivers of children with ASD to better manage the stressors and daily challenges over which they had little control. The intervention emphasised the strengthening of skills that were protective for health and reducing factors associated with poorer health, the caregivers reporting reductions in carer burden, depression and mood disturbances (Ruiz-Robledillo & Moya-Albiol, 2015).

Much of the research evaluating interventions with parents of children with complex needs to date has, understandably, focused on the challenges faced by families and trying to reduce parental stress (Barrett & Heubeck, 2000). However, parent well-being is not just defined by the absence of significant stress (Hastings & Beck, 2004). Kuhanek et al. (2015) suggest a different approach to research on family functioning, instead focusing on coping and resiliency, hopefulness and quality of life. What is becoming much clearer is that parents enjoy even very small achievements and are able to find the positives and obtain meaning, purpose and personal growth through caring for a child with complex needs (Dykens, 2015). This occurs even when that care is intense and draining and requires their (continuous partial) attention 24 hours a day, seven days a week. A key part of supporting parents and families is to assist them to find the positive uplifts and gain maximum impact from them, combined with respite provided by competent, caring staff who allow parents to take breaks from their caring role and turn off the vigilance for even short periods. Taken together, these two approaches may enable parents to sustain a level of caring that in many cases is truly remarkable.

10.4 Conclusion: Making the invisible visible

In order to advocate for the need for support services for parents of children with complex needs, the work of caring that the parents undertake on a daily basis must be made more visible. Parents struggle with a lack of recognition of their needs and a difficulty in obtaining services for their child if the child's illness is not physically visible (Medway et al., 2015; Novak, Lingam, Coad, & Emond, 2012). This is particularly apparent in children with acquired brain injuries or ASD for example, where the often 'normal' appearance of the child belies the significant disability/disabilities the child may have and reduces the tolerance of others when the child displays challenging or not age appropriate behaviour (Jordan & Linden, 2013; National People with Disabilities and Carer Council, 2009). Much of the work undertaken by parents of children with ASD is hidden work (cognitive work involved in planning, preparation and vigilance), making it difficult for these mothers to access support and respite (Safe et al., 2012). It is hoped this work may become more visible in light of the considerable research occurring with

families of children with ASD, but there are still disproportionately few studies exploring the concerns of parents caring for a child with intellectual disabilities, but not ASD, despite the similar prevalence rates (Dykens, 2015).

The move toward a National Disability Insurance Scheme (NDIS) in Australia has provided an opportunity for people with disabilities and their families to become more visible. The NDIS is delivered under the auspices of the National Disability Insurance Agency and was introduced on 1st July 2013 following a Productivity Commission report that identified significant funding and support gaps in the existing disability support system (Buckmaster, 2012). To be eligible for a support package under the NDIS, participants must have a permanent (or likely to be permanent) intellectual, cognitive, neurological, sensory or physical impairment, or impairment due to a psychiatric condition and this impairment results in a 'substantially reduced capacity' to undertake activities such as communication, social interaction, leaning, mobility, self-care or self-management (Office of Parliamentary Counsel, 2014).

Various reports and submissions to taskforces have occurred in the lead up to the introduction of the NDIS (see for example Carer Payment (child) Review Taskforce, 2007; Lester & Reid, 2007; National People with Disabilities and Carer Council, 2009). These reports and the work of organisations such as *Every Australian Counts* (http://www.everyaustraliancounts.com.au/) are contributing to a greater awareness of people with disabilities and their families. The reported large increase in the cost of the NDIS (Conifer, 2015; Cullen, 2013) is in large part due to the initial lack of accurate data regarding the numbers of people who would be eligible for assistance under the scheme, highlighting just how invisible these children and adults, and their families, are within the Australian community.

Bourke-Taylor et al. (2013) argue that research is needed to identify the real-life challenges experienced by families caring for children with complex needs. Safe et al. (2012) suggest that further research is required to highlight the hidden work of parents of children with ASD. The studies contained within the research program presented in this thesis contribute to addressing both of these deficits by providing insight into

aspects of the parental caregiving experience and the impact on family and home life. These include the significant time expenditure and intensity of the parental caregiving role, the intense vigilance required by many parents to ensure their child's safety (or the safety of others) and monitor their child's condition, the tensions for mothers in having to undertake tasks that they actively dislike doing, but that are needed to meet the mainly healthcare or functional needs of their child, and the changes to home life that occur when living with a child with ASD.

The aim of the research program was making visible the often invisible work of caring for a child with complex needs. Each of the studies contained within the research program contributed to this aim. The systematic reviews summarised and synthesised the existing time use, including night care research, making the findings from research in this area more accessible and available for translation into practice. The time use study and the pilot study exploring the competence, importance and enjoyment of childcare related activities provide an important (and previously missing) level of detail regarding what is occurring in the daily lives of mothers of children with complex needs and how they feel about some of the activities they undertake for their children. The innovative approach to exploring home life used in the photo-interview study provides information about an aspect of caring for a child with ASD that has been almost totally ignored in research to date.

The multi method approach used in the research program has been a key factor in being able to achieve the aim. In particular, the qualitative aspects provide a context for the quantitative components. Fully understanding the factors impacting on the sleep length of parents of children with complex needs, particularly the heightened awareness and need for constant vigilance overnight would not have been possible without the inclusion of the qualitative research in that area. The key informants and the photo interview study provided a greater understanding of the impact that caring for a child with complex needs, particularly a child with ASD, has on mothers, the wider family and the home environment.

The story that emerged through the individual studies contained within this research program provided the context for a rethinking of the vigilance required by parents of children with complex needs, the continuous partial attention theory. It is hoped that viewing the caregiving role of parents of children with complex needs through the lens of continuous partial attention may contribute a much better understanding of why parents of children with complex needs find the caregiving experience uplifting, but also draining and exhausting, with an emphasis on the importance of these parents receiving a break from the caregiving to enable them to switch off, even briefly, from the responsibility that they carry. Perhaps more importantly, viewing the vigilance required by parents of children with complex needs as a form of continuous partial attention has the potential to suggest better ways of supporting these parents, with the aim of improving their physical, mental and emotional health.

Parents of children with complex needs argue that they are not heroes, they just do what they have to do because they love their children (Carnevale et al., 2006; Lester & Reid, 2007). They also may choose not to accept the tragedy discourse that is frequently applied to children with disabilities and their families (Broberg, 2011). But the fact that some parents of children with complex needs get to crisis or breaking point and feel forced to place their children in out of home care demonstrates that the support offered to these parents is often inadequate or not provided in a way that genuinely assists the children, parents and families to lead positive lives.

The NDIS provides a unique opportunity in Australia to provide individualised support to children and adults with disabilities and their families. Further research into the most effective and appropriate way to provide that support is needed however, to ensure that this opportunity is not missed. Parents of children with complex needs provide a remarkable level of care, but this care takes a physical, mental and emotional toll on the parents and the family. Finding a way to support these parents in a manner that emphasises the positives, reduces the burden in areas that they find most difficult, and strengthens family relationships needs to be a primary focus for researchers and health professionals involved in the care of children with complex needs and their families.

10.5 Recommendations for practice

A number of recommendations arise from the findings contained within this thesis. While all the recommendations have a potential impact on service delivery, some relate specifically to clinicians and policy makers, whilst others provide direction to guide future research in this area. The recommendations have particular relevance to Australia in the context of the roll out of the NDIS, but can also be applied to the international context.

Recommendations for clinicians and policymakers:

- Parental caregivers need regular breaks from their caregiving role in the form of individualised, flexible respite that meets the needs of the child with complex needs and the family. This respite care needs to be provided by carers and healthcare professionals who are well trained, well supported and have sufficient scope of practice to manage the care needs of the child and gain the trust of the parents.

- The provision of respite care needs to be an accepted and acknowledged part of care packages negotiated for children with complex needs covered by the NDIS. This is of particular importance for children with ASD and other types of intellectual disability, particularly those children with severe behaviours.

- Healthcare professionals prescribing treatments for a child with complex needs need to balance the therapy and development requirements of the child with the needs of the parent and family. In particular, conversations need to occur between healthcare professionals and parents that acknowledge the importance of the parent role and provide strategies that assist parents to maximise the opportunities for them to meet the treatment needs of their child, but also have opportunities to enjoy the positive benefits derived from time spent being a parent, with no therapy responsibilities.

- The type and amount of home modification and adaptation required in families living with a child with complex needs, particularly children with ASD or intellectual disability, needs to be better understood in order to ensure that the requirement and justification for this service can be more clearly accepted and incorporated into care packages provided through the NDIS where appropriate. This is an area that is currently poorly acknowledged or understood by policy makers and service providers working within the NDIS, as evidenced by the minimal information and guidelines currently available, and needs to be urgently addressed as part of the national roll out of the scheme.

Recommendations to guide future research:

- Research is needed to ascertain the most effective models of service delivery for the provision of respite care, particularly for children with severe behaviours. The evaluation of these models need to incorporate cost benefit analyses that take into consideration the costs of providing and resourcing the service, and the potential savings for the healthcare and social service sectors with regard to improved caregiver health and reduced demand for out of home placement.

- More research is needed to identify interventions that are effective in improving the health of parental caregivers by providing opportunities and strategies for the parents that maximise the positive uplifts, increase health promoting behaviours and reduce caregiver burden and stress. The evaluation of the effectiveness of these interventions should include a focus on positive benefits such as improved family functioning, coping, resilience, hopefulness and quality of life, in addition to reductions in negative consequences such as high caregiver stress levels and poor mental health.

- New approaches need to be taken in research with parents of children with complex needs to better understand the vigilance required and the impact this has on caregivers' mental, emotional and physical health. Current approaches to time use

research with parents of children with complex needs are onerous for the parents and poorly capture the intensity of the caregiving experience. Better methods are needed to fully measure the type and amount of care provided by parents in order to ensure that parental caregivers are adequately supported to maintain their caregiving role.

10.6 References

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Chapter 11 - Appendices

11.1 Appendix 1: Ethics approval and documentation (Time use study)

Social Science Ethics Officer
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MEMORANDUM

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

UTAS

'FULL COMMITTEE' ETHICS APPLICATION APPROVAL

19 July 2010

AssocProf Rosalind Bull
Nursing and Midwifery
Private Bag 1322
Launceston

Ethics Reference: H11241

Caring for children with complex needs

Student: Damhnat McCann (PhD)

Dear AssocProf Bull

The Tasmania Social Sciences HREC Ethics Committee approved the above project on 19 July 2010.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or human.ethics@utas.edu.au.

3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.

4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.

5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**

6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Melanie Horder
Ethics Officer

Dear Parent or Carer

We would like to invite you to take part in a research project being conducted through the School of Nursing and Midwifery at the University of Tasmania. This study is being conducted in partial fulfilment of a PhD for Damhnat McCann, under the supervision of Associate Professor Rosalind Bull and Dr Tania Winzenberg.

We are inviting you to be involved because you are the primary carer of a child who currently attends, or is eligible to attend, the St Giles Respite Centre or another service provided by St Giles. The staff at St Giles have agreed to post out this letter for us so that we can tell you about the project and give you an opportunity to be part of it. Please note that your private details, including your address and any information relating to you or your child, have not been given to us and will not be given to us unless you give permission for this to happen.

The key reason for doing this project is to get better information about the type and level of care that parents are providing for their child with special needs at home every day. We hope that having this information might assist in better planning for the range of support services that are currently offered to families.

If you agree to be part of this research project, you will be asked to use a diary for two 24 hour periods. To fill in this diary, you will need to write in all the activities you do during these two days and nights. As part of the study, we will also ask you to answer some short questions about your family and the needs of your child.

Please find enclosed an information sheet about the project that includes my contact information in case you have questions. If you think you might like to be part of the project, please fill in your details on the blue form and post it to me in the envelope provided. I will then contact you to explain the project in more detail and you can decide whether or not you would like to be involved.

With thanks

Damhnat McCann
PhD student & Senior Lecturer, School of Nursing & Midwifery
University of Tasmania

Dear Parent or Carer

We would like to invite you to take part in a research project being conducted through the School of Nursing and Midwifery at the University of Tasmania. This study is being conducted in partial fulfilment of a PhD for Damhnat McCann, under the supervision of Associate Professor Rosalind Bull and Dr Tania Winzenberg.

We are inviting you to be involved because you are the primary carer of a child who is attending the Christmas Camp at Launceston Church Grammar School. The staff at Launceston Church Grammar School have given permission for us to distribute this information about the project and give you an opportunity to be part of it. Please note that your private details, including your address and any information relating to you or your child, have not been given to us and will not be given to us unless you give permission for this to happen.

The key reason for doing this project is to get better information about the type and level of care that parents are providing for their child with special needs at home every day. We hope that having this information might assist in better planning for the range of support services that are currently offered to families.

If you agree to be part of this research project, you will be asked to use a diary for two 24 hour periods. To fill in this diary, you will need to write in all the activities you do during these two days and nights. As part of the study, we will also ask you to answer some short questions about your family and the needs of your child.

Please find enclosed an information sheet about the project that includes my contact information in case you have questions. If you think you might like to be part of the project, please fill in your details on the blue form and post it to me in the envelope provided. I will then contact you to explain the project in more detail and you can decide whether or not you would like to be involved.

With thanks

Damhnat McCann
PhD student & Senior Lecturer, School of Nursing & Midwifery
University of Tasmania

Yes, I would like to be contacted so that I can find out more about the ‘Caring for children with complex needs’ research project.

Name:
.....

Phone:
.....

Preferred contact time:
.....

CARING FOR CHILDREN WITH COMPLEX NEEDS: TIME USE DIARY

(Participant information sheet version 3- 12/01/2011)

Invitation

You are invited to participate in a research study into the type of care that parents give to their children with special needs at home. This study is being conducted in partial fulfillment of a PhD for Damhnat McCann, under the supervision of Associate Professor Rosalind Bull and Dr Tania Winzenberg.

The study is being conducted by:
Damhnat McCann, PhD student at the School of Nursing & Midwifery, UTAS
Assoc Professor Rosalind Bull, Director of Teaching & Learning, School of Nursing & Midwifery, UTAS
Dr Tania Winzenberg, Senior Research Fellow, General Practice, Menzies Research Institute

1. 'What is the purpose of this study?'

The purpose of this study is to explore what it is like to be the parent of a child with special needs. This study aims to get information about the type and level of care that parents provide for their children, particularly a child or children with special needs. This information will be used to inform policy makers and service providers who provide services for people with disabilities, in the hope of better targeting the provision of services.

2. 'Why have I been invited to participate in this study?'

You have been invited to be part of this study because you have at least one child who has a disability or disabilities and attends, or is eligible to attend the St Giles Respite Centre or another service provided by St Giles; or has attended a Christmas Holiday Camp at Launceston Church Grammar School; or you have responded to a newsletter advertisement.

4. 'What does this study involve?'

This study has two parts. In the first part of the study, you will be asked to fill in a diary for two days and answer some questions. This information sheet will explain what is involved in that part of the study.
The second part of the study involves parents taking photographs and then having an interview with one of the researchers (Damhnat McCann). A second information sheet is available to explain that part of the study if you think that you might like to participate.

For the first part of the study, you will be asked to fill in a diary for two 24 hour periods, one during the week and one on the weekend. You will be asked to write down every activity that you do in the diary for the two days and nights and also put in some details about who you are doing it for and any other activities that you are doing at the same time. You will need to be careful to include all the activities that you do, even ones that only take a few minutes. The diary is designed to make it easy for you to fill in all the activities and there is an example to follow. You will also be asked some questions about time pressures, your child and the type of disability that they have, the health care services that your family uses and how you access these services.

There will a second short questionnaire to fill in a few weeks after finishing the diary. That questionnaire will be posted to you and you will be asked to send it back in the provided envelope. This second questionnaire will only take 5-10 minutes to complete.

It is important that you understand that your involvement is this study is voluntary. While we would be pleased to have you participate, we respect your right to decline. There will be no consequences to you if you decide not to participate, and this will not affect any treatment or service that you receive. You can stop being a part of the study at any time without giving any reason. All information will be treated in a confidential manner, and your name will not be used in any publication arising out of the research. All of the research will be kept in a locked cabinet or on a password protected computer or USB in the office of Damhnat McCann and will be destroyed by shredding the documents and permanently deleting the electronic information 5 years after the study findings have been published.

5. Are there any possible benefits from participation in this study?

Being part of this research gives you the opportunity to describe the type and level of care that you provide for your child or children. This information has not been collected in this type of detail before and we are hoping that it might assist those who plan and deliver support and healthcare for children with special needs and their families.

If we are able to take the findings of this small study and link them with a wider study, it may lead to further research aimed at developing appropriate support services to benefit children with special needs and their families.

6. Are there any possible risks from participation in this study?

There are no specific risks anticipated with participation in this study. However, if you find that being part of this study raises upsetting issues for you, Carers Tasmania provides counselling services that you would be able to access. Carers Tasmania is available by phoning (03) 6231 5507 or 1800 242 636 or via: http://www.carersaustralia.com.au/?/contacts/view/285.

7. What if I have questions about this research?

If you would like to discuss any aspect of this study please feel free to contact Damhnat McCann (ph 6324 3812) and I will be happy to discuss any aspect of the research with you. Once we have analysed the information, we will be mailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study you should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H11241.

Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.

CONSENT FORM

(Participant consent form version 1- 23/05/2010)

Caring for children with complex needs: **Time use diary**

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1. I have read and understood the 'Information Sheet' for this part of the project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves me filling in a diary for two 24 hour periods and completing five questionnaires, four before I fill in the diary and another one a few weeks after completing the diary.
4. I understand that all research data will be securely stored on the University of Tasmania premises for five years, and will then be destroyed.
5. Any questions that I have asked have been answered to my satisfaction.
6. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
7. I understand that the researchers will maintain my confidentiality and that any information I supply to the researchers will be used only for the purposes of the research.
8. I agree to participate in this research and understand that I may withdraw at any time without any effect, and that I may request that any data I have supplied to date be withdrawn from the research.

Name of Participant:

Signature: Date:

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Investigator

Signature of Investigator

CARING FOR CHILDREN WITH COMPLEX NEEDS: PHOTO INTERVIEW

(Participant information sheet version 2- 27/05/2011)

Invitation

You are invited to participate in the second part of a research study into the type of care that parents give to their children with special needs at home. This study is being conducted in partial fulfillment of a PhD for Damhnat McCann, under the supervision of Associate Professor Rosalind Bull and Dr Tania Winzenberg.

The study is being conducted by:
Damhnat McCann, PhD student at the School of Nursing & Midwifery, UTAS
Associate Professor Rosalind Bull, Director of Teaching & Learning, School of Nursing & Midwifery, UTAS
Dr Tania Winzenberg, Senior Research Fellow, General Practice, Menzies Research Institute

2. 'What is the purpose of this second part of the study?'
The overall purpose of the study is to explore what it is like to be the parent of a child with special needs. The key purpose of the second part of the study is to explore in detail, through the eyes of the parents, the daily experience of caring for a child with special needs at home

2. 'Why have I been invited to participate in the second part of the study?'

You have been invited to participate in the second part of the study because you have already chosen to participate in the study by completing the diary.

4. 'What does the second part of the study involve?'

This second part of the study would involve you taking photographs that describe your home life and then having an interview with one of the researchers (Damhnat McCann) to discuss the photos and what they mean. It is entirely up to you what aspects of your life you choose to photograph or not photograph. What we hope is that you will take photographs that can help us to understand what it is like to be the parent of a child with special needs.

The photos should be taken around the time that you are filling in the two diary days, although it does not have to be the same days. Once you have taken the photos, we will ask you to choose your favourite 6 photos. We will then arrange a time and place that suits you so that you can discuss the photos and what they mean in an interview with Damhnat. The interview will take approximately one hour and will be recorded on an iPod so that it can be typed up later.

During the interview, Damhnat will ask whether you are happy for the photos that you have chosen for the interview to be used in papers that are published about the study and at conference presentations. You do not have to consent for any photos to be used in this way, or you can choose photos that you are happy to have

used. You can still do the photo and interview part of the study even if you don't want your photographs to be used in publications or presentations.

If you agree, we might also use parts of the recorded interview in conference presentations. These parts of the interview would have your voice, but you would not be identified in any way. You need to know that you can also choose not to have any part of your interview used in this way.

It is important that you understand that your involvement is this study is voluntary. While we would be pleased to have you participate, we respect your right to decline. There will be no consequences to you if you decide not to participate, and this will not affect any treatment or service you receive. You can stop being a part of the study at any time without giving any reason. All information will be treated in a confidential manner, and your name will not be used in any publication arising out of the research. All of the research will be kept in a locked cabinet or on a password protected computer or USB in the office of Damhnat McCann and will be destroyed by shredding the documents and permanently deleting the electronic information 5 years after the study findings have been published. If you give permission for your photographs or recording to be used, but later change your mind, then you can contact Damhnat and your photos or recordings will be removed from any publications or presentations. Please note that this cannot happen if papers are already published or presentations have already happened. We would be happy for you to contact us at any time to discuss this.

5. Are there any possible benefits from participation in this study?

Being part of this research gives you the opportunity to have a voice and tell people about the experience of caring for a child with special needs. It is entirely up to you how much information you want to share about this. We hope that giving parents a voice will help others to understand more fully what it is like to parent a child with special needs.

6. Are there any possible risks from participation in this study?

If you find that being part of this aspect of the study raises upsetting issues for you, Carers Tasmania provides counselling services that you would be able to access. Carers Tasmania are available by phoning (03) 6231 5507 or 1800 242 636 or via: http://www.carersaustralia.com.au/?/contacts/view/285. There is a chance that other people may be able to identify you or your family members through photographs that are used in publications or presentations. This is why we are asking you to choose the photos that are used, and how they are used.

7. What if I have questions about this research?

If you would like to discuss any aspect of this study please feel free to contact Damhnat McCann (ph 6324 3812) and I will be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study you should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H11241.

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

CONSENT FORM

(Consent form version 1- 23/05/2010)

CARING FOR A CHILD WITH COMPLEX NEEDS: PHOTO INTERVIEW

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1. I have read and understood the 'Information Sheet' for this part of the project.
2. The nature and possible effects of the study have been explained to me.
3. I understand that this part of the study involves me taking photographs that reflect what it is like for me to be the parent of a child with special needs and then taking part in an interview to discuss these photographs. I understand that the interview will be recorded on an iPod.
4. I understand that if I become upset during this part of the study, the researchers will provide me with details of support services provided through Carers Tasmania. Carers Tasmania is available by phoning (03) 6231 5507 or 1800 242 636 or via: http://www.carersaustralia.com.au/?/contacts/view/285.
5. I understand that research data will be securely stored on the University of Tasmania premises.
6. Any questions that I have asked have been answered to my satisfaction.
7. I understand that if I give consent, photographs and/or parts of the recording from my interview may be used in publications or presentations related to this research and this may mean that I or members of my family are identifiable. I understand that I can participate in the photo interview, but not give consent for my photographs and/or parts of the recording to be used in publications or presentations. I agree that any other research data gathered from me may be published provided that I cannot be identified as a participant.

I consent to have chosen photographs (*please nominate specific photos*.....

.....) **used in publications and / or presentations.**

Name of Participant:

Signature: Date:

I consent to have audio from my interview used in conference presentations

Name of Participant:

Signature: Date:

8. I understand that the researchers will protect my identity and that information I supply to the researchers will be treated as confidential and will be used only for the purposes of the research.
9. I agree to participate in this research and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data (including photographs) that I have supplied be withdrawn from the research, unless it has already been used in a publication or presentation.

General consent

Name of Participant:

Signature: Date:

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Investigator

Signature of Investigator

11.2 Appendix 2: Ethics approval and documentation (Autism & home study)

Social Science Ethics Officer
Private Bag 01 Hobart
Tasmania 7001 Australia
Tel: (03) 6226 2763
Fax: (03) 6226 7148
Katherine.Shaw@utas.edu.au

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

28 November 2011

Dr Ceridwen Owen
School of Architecture and Design
Locked Bag 1323
Launceston Tasmania

Dear Dr Owen

Re: FULL ETHICS APPLICATION APPROVAL
Ethics Ref: **H0012135 - At home with Autism: A study of the transforming meanings of 'home' from the perspective of carers of children with Autism Spectrum Disorder**

We are pleased to advise that the Tasmania Social Sciences Human Research Ethics Committee approved the above project on 25 November 2011.

Please note that this approval is for four years and is conditional upon receipt of an annual Progress Report. Ethics approval for this project will lapse if a Progress Report is not submitted.

The following conditions apply to this approval. Failure to abide by these conditions may result in suspension or discontinuation of approval.

1. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval, to ensure the project is conducted as approved by the Ethics Committee, and to notify the Committee if any investigators are added to, or cease involvement with, the project.

2. Complaints: If any complaints are received or ethical issues arise during the course of the project, investigators should advise the Executive Officer of the Ethics Committee on 03 6226 7479 or human.ethics@utas.edu.au.

3. Incidents or adverse effects: Investigators should notify the Ethics Committee immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.

4. Amendments to Project: Modifications to the project must not proceed until approval is obtained from the Ethics Committee. Please submit an Amendment Form (available on our website) to notify the Ethics Committee of the proposed modifications.

5. Annual Report: Continued approval for this project is dependent on the submission of a Progress Report by the anniversary date of your approval. You will be sent a courtesy reminder closer to this date. **Failure to submit a Progress Report will mean that ethics approval for this project will lapse.**

6. Final Report: A Final Report and a copy of any published material arising from the project, either in full or abstract, must be provided at the end of the project.

Yours sincerely

Katherine Shaw
Acting Executive Officer

Social Science Ethics Officer
Private Bag 01 Hobart
Tasmania 7001 Australia
Tel: (03) 6226 2763
Fax: (03) 6226 7148
Katherine.Shaw@utas.edu.au

HUMAN RESEARCH ETHICS COMMITTEE (TASMANIA) NETWORK

UTAS

23 August 2012

Dr Ceridwen Owen
School of Architecture and Design
Locked Bag 1323
Launceston Tasmania

Sent via email

Dear Dr Owen

Re: APPROVAL FOR AMENDMENT TO CURRENT PROJECT
Ethics Ref: **H0012135 - At home with Autism: A study of the transforming meanings of 'home' from the perspective of carers of children with Autism Spectrum Disorder**

1. Amendment for the researchers to attend parent group meetings at Autism Tasmania to distribute study information.
2. Mary Brake, Autism Consultant with the Tasmanian Department of Education, to distribute information sheets to parents of children with ASD.
3. Revised information sheet.

We are pleased to advise that the Chair of the Tasmania Social Sciences Human Research Ethics Committee approved the Amendment to the above project on 21 August 2012.

Yours sincerely

Katherine Shaw
Ethics Officer
Tasmania Social Sciences HREC

AT HOME WITH AUTISM: PHOTO INTERVIEW

(Participant information sheet version 03-18/11/2011)

Invitation

You are invited to participate in a research study that asks parents or primary carers to reflect on their home life with a child or children with Autism Spectrum Disorder

The study is being conducted by:
Dr Ceridwen Owen, Lecturer at the School of Architecture & Design, UTAS
Damhnat McCann, Senior Lecturer at the School of Nursing & Midwifery, UTAS

3. 'What is the purpose of this study?'
The overall purpose of this study is to explore in detail, through the eyes of parents or primary carers, the home environment in the daily experience of caring for a child or children with ASD.

2. 'Why have I been invited to participate in this study?'

You have been invited to participate in this study because you are the parent or primary carer of a child or children with ASD and you have received information about the study via Autism Tasmania or the Giant Steps School or other support organisation; or through staff at the Department of Education.

3. 'What does the study involve?'

This study would involve you taking photographs that describe your home environment in the daily experience of caring for a child or children with ASD and then having an interview with the researchers (Ceridwen Owen and Damhnat McCann) to discuss the photos and what they mean. It is entirely up to you what aspects of your home environment you choose to photograph or not photograph. What we hope is that you will take photographs that can help us to better understand what your home and family life is like focusing on any changes that you have made to the home environment to assist your child or children with ASD and/or make it a safer environment for your child or children

We will supply the digital camera, a pre-paid post pack and journal booklet (the journal is just to help us to understand why you chose to take those photos). Once you have taken the photos on the camera (and removed any photographs that you do not want to use) we will ask you to make some brief notes about the photos in the journal booklet and post it and the camera back to us. We will then arrange a time and place that suits you so that you can discuss the photos and what they mean in an interview with Ceridwen and Damhnat. We will print out your photos from the camera and bring them and the journal booklet to the interview. The interview will take up to an hour and will be recorded on an iPod so that it can be typed up later. The interview can be held either at the university, or at any place that you choose and will take no more than an hour.

During the interview, we will ask whether you are happy for the photos that you have chosen for the interview to be used in papers that are published about the study and at conference presentations. You do not have to consent for any photos to be used in this way, or you can choose photos that you are happy to have used. You can still do the photo and interview part of the study even if you don't want your photographs to be used in publications or presentations. If you agree, we might also use parts of the recorded interview in conference

presentations. These parts of the interview would have your voice, but you would not be identified in any way. You need to know that you can also choose not to have any part of your interview used in this way.

It is important that you understand that your involvement is this study is voluntary. While we would be pleased to have you participate, we respect your right to decline. There will be no consequences to you if you decide not to participate, and this will not affect any treatment or service you receive. You can stop being a part of the study at any time without giving any reason. All information will be treated in a confidential manner, and your name will not be used in any publication arising out of the research. All of the research will be kept in a locked cabinet or on a password protected server or USB in the office of Dr Ceridwen Owen and will be destroyed by shredding the documents and permanently deleting the electronic information 5 years after the study findings have been published. If you give permission for your photographs or recording to be used, but later change your mind, then you can contact either Ceridwen or Damhnat and your photos or recordings will be removed from any publications or presentations. Please note that this cannot happen if papers are already published or presentations have already happened. We would be happy for you to contact us at any time to discuss this.

4. Are there any possible benefits from participation in this study?

It has been argued that parents of children with complex needs are a 'silent voice' within our society. We hope that this research will provide an opportunity for you to describe your experiences of being the parent of a child with ASD, providing insight into what that role entails and the positive and/or negative impact that this has on your family and home life. It is entirely up to you how much information you want to share about this. There is a growing recognition of the benefits to children with complex needs, including ASD, of being cared for in a supportive home environment and a push to commence early intervention programs, many of them home based, to support children with ASD to engage with their wider communities. But we have limited understanding about how these policy initiatives impact on the home life of families caring for a child with ASD. This research will increase awareness in this area, perhaps providing additional data to inform those making policy decisions and the organisations that support children with ASD and their families.

5. Are there any possible risks from participation in this study?

If you find that being part of this aspect of the study raises upsetting issues for you, Carers Tasmania provides counselling services that you would be able to access. Carers Tasmania are available by phoning (03) 6231 5507 or **1800 242 636 or via:** http://www.carersaustralia.com.au/?/contacts/view/285. There is a chance that other people may be able to identify you or your family members through photographs that are used in publications or presentations. This is why we are asking you to choose the photos that are used, and how they are used.

6. What if I have questions about this research?

If you would like to discuss any aspect of this study please feel free to contact Ceridwen Owen (ph. 6324 4479) or Damhnat McCann (ph 6324 3812) and we will be happy to discuss any aspect of the research with you. Once we have analysed the information we will be mailing you a summary of our findings. You are welcome to contact us at that time to discuss any issue relating to the research study.

This study has been approved by the Tasmanian Social Science Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study you should contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H12135.

Thank you for taking the time to consider this study. If you wish to take part in it, please sign the attached consent form under 'general consent'. This information sheet is for you to keep.

CONSENT FORM

(Consent form version 3- 18/11/2011)

AT HOME WITH AUTISM: PHOTO INTERVIEW

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1. I have read and understood the 'Information Sheet' for this project.
2. The nature and possible effects of the study have been explained to me.
3. I understand this study involves me taking photographs that reflect on my home life focusing on modifications to the home environment to support my child (or children) with Autism Spectrum Disorder and then taking part in an interview to discuss these photographs. I understand that the interview will be recorded on an iPod.
4. I understand that if I become upset during this part of the study, I am able to access support services provided through Carers Tasmania. Carers Tasmania is available by phoning (03) 6231 5507 or 1800 242 636 or via: http://www.carersaustralia.com.au/?/contacts/view/285.
5. I understand that research data will be securely stored on the University of Tasmania premises and that this data will be destroyed 5 years after publication of a paper about this research.
6. Any questions that I have asked have been answered to my satisfaction.
7. I understand that if I give consent, photographs and/or parts of the recording from my interview may be used in publications or presentations related to this research and this may mean that I or members of my family are identifiable. I understand that I can participate in the photo interview, but not give consent for my photographs and/or parts of the recording to be used in publications or presentations. I agree that any other research data gathered from me may be published provided that I cannot be identified as a participant.
8. I understand that the researchers will protect my identity and that information I supply to the researchers will be treated as confidential and will be used only for the purposes of the research.
9. I agree to participate in this research and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data (including photographs) that I have supplied be withdrawn from the research, unless it has already been used in a publication or presentation.

To be signed and returned to investigators prior to research task:

General consent

Name of Participant:

Signature: Date:

Statement by Investigator

☐ I have explained the project & the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet where my details have been provided so participants have the opportunity to contact me prior to consenting to participate in this project.

Name of Investigator

Signature of Investigator

To be signed at interview (if applicable):

I consent to have chosen photographs (*please nominate specific photos**.....***

.....) **used in publications and / or presentations.**

Name of Participant:

Signature: Date:

To be signed at interview (if applicable):

I consent to have audio from my interview used in conference presentations

Name of Participant:

Signature: Date:

11.3 Appendix 3: Demographic questionnaire

This questionnaire has been removed for copyright or proprietary reasons.

11.4 Appendix 4: Time use diary

Time Use Diary[8]

[8] Adapted from: Australian Bureau of Statistics (2008). Time Use Survey 2006. Time use diary (Time use survey: User guide 2006, Cat. No. 4150.0). Retrieved from http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/01AC26F86E989B2FCA2573F5001528F1/$File/41500%20tus%202006%20diary.pdf

Where does the day go?

To fill in the diary:

• Write down your main activity (e.g. at work, cooking, childminding, watching television, etc.)

• Write down who you did this activity for (e.g. self, a child or children, other family member, a friend, work, organisation/community)

• Write down anything else you did at the same time (e.g. eating or drinking, childminding, watching television, listening to the radio, talking to a neighbour)

• Write down where you were (e.g. at work, home, shops, park, doctor, driving or riding in a car or bus, etc.)

Please make sure that you:

• Look at the diary example

• Record your activities in as much detail as possible

• Complete the diary for both days, beginning at 12 midnight and covering the full 24 hour period for each day

• When recording activities related to the care of a child, please detail which child is receiving the care based on the information you put in the background questions on page 2 (please see the example diary for an example of how to do this)

• Complete the questions on the last page for each diary day

Background questions

1. How many children do you have?

1. 1 child
2. 2 children
3. 3 children
4. 4 children
5. 5 children
6. 6 children
7. ..... children

2. It is important that you are specific about the activities that you do for each of your children in the diary. To help with this, please number each of your children (eg. 1, 2 etc) and then answer the following questions for each child

Child 1

Age of child .....

Does this child have special care needs? Yes No

Child 2

Age of child .....

Does this child have special care needs? Yes No

Child 3

Age of child .....

Does this child have special care needs? Yes No

Child 4

Age of child .....

Does this child have special care needs? Yes No

Child 5

Age of child .....

Does this child have special care needs? Yes No

Child 6

Age of child .....

Does this child have special care needs? Yes No

Child 7

Age of child .....

Does this child have special care needs? Yes No

Day 1 (Name of the day?.....) 12midnight – 3am

0.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 3am – 6am

	What was your main activity? (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 6am – 9am

6.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 9am – 12noon

9.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 12noon – 3pm

12.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 3pm – 6pm

3.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 6pm – 9pm

6.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 1 9pm – 12midnight

9.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Diary day questions – Day 1

Please circle the correct answer for each question.

1. Do you usually work in a paid job on .....?

1. Yes
2. No

2. What type of day was today?

1. A usual day
2. It was a holiday (e.g. public holiday, leave, flex/RDO, award day off)
3. I was sick or injured
4. I took time off from normal activities:
    a. to do extra work paid/unpaid
    b. to arrange personal/family matters
    c. to look after a sick/injured person
    d. for a special leisure/educational/ religious/community/family activity(e.g. sports event, course, conference, festival, wedding, etc)
    e. Cared for children during school holiday/pupil free day (not weekend)
    f. Other (please specify).....

Day 2 (Name of the day?.....) 12midnight – 3am

0.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 3am – 6am

	What was your main activity? (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 6am – 9am

6.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 9am – 12pm

	What was your main activity? (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 12pm – 3pm

12.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 3pm – 6pm

3.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 6pm – 9pm

6.00	**What was your main activity?** (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Day 2 9pm – 12midnight

	What was your main activity? (Please record all activities, even if they only lasted a few minutes)	**Who did you do this for?** (eg. child 1, 2, 3 etc., self, friend, work, partner/wife/husband, a charity, relative)	**What else were you doing at the same time?** (eg. minding child 1, 2 etc, watching television, listening to the radio)	**Where were you?** (eg. At home, work, on a bus, driving the car)
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Diary day questions – Day 2

Please circle the correct answer for each question.

1. Do you usually work in a paid job on .....?

3. Yes
4. No

2. What type of day was today?

5. A usual day
6. It was a holiday (e.g. public holiday, leave, flex/RDO, award day off)
7. I was sick or injured
8. I took time off from normal activities:
    a. to do extra work paid/unpaid
    b. to arrange personal/family matters
    c. to look after a sick/injured person
    d. for a special leisure/educational/ religious/community/family activity(e.g. sports event, course, conference, festival, wedding, etc)
    e. Cared for children during school holiday/pupil free day (not weekend)
    f. Other (please specify).....

11.5 Appendix 5: Child's Challenging Behaviour Scale

CHILD'S CHALLENGING BEHAVIOUR SCALE (Bourke-Taylor, Law & Howie, 2010)[9]

At times, children and teenagers behave in challenging ways. The following statements relate to your child's behaviour at home. Please read each statement and select the most appropriate category representing your level of agreement.

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
My child does not usually yell and scream when things do no go his/her way	◯	◯	◯	◯	◯
My child never has tantrums	◯	◯	◯	◯	◯
My child aggravates others	◯	◯	◯	◯	◯
My child is never aggressive and violent towards others	◯	◯	◯	◯	◯
My child does not mind when I leave them at home with another adult while I go out	◯	◯	◯	◯	◯
My child can be stubborn and uncooperative	◯	◯	◯	◯	◯
I am able to manage my child's behaviour easily at home	◯	◯	◯	◯	◯
I am able to manage the most challenging and difficult behaviours effectively on my own at home	◯	◯	◯	◯	◯
My child is happy and content at home most of the time	◯	◯	◯	◯	◯
My child follows the family routine easily	◯	◯	◯	◯	◯
My child copes well with disruptions to the family routine	◯	◯	◯	◯	◯

[9] Retrieved from: http://www.autismalert.org/uploads/PDF/MANAGEMENT--Childs%20Challenging%20Behavior%20Scale.pdf

11.6 Appendix 6: Amount of Assistance Questionnaire

This questionnaire has been removed for copyright or proprietary reasons.

11.7 Appendix 7: Time Crunch Scale

This scale has been removed for copyright or proprietary reasons.

11.8 Appendix 8: Revised coding structure for the Australian Time Use Survey

This coding structure has been removed for copyright or proprietary reasons.

11.9 Appendix 9: Poster presentation ACCYPN conference (Melbourne) 2012

Title

The night shift: sleep deprivation in parents caring for children with complex needs

Author

McCann, Damhnat

Affiliation

University of Tasmania, Launceston, Australia

Aim

Approximately 1 in 12 children in Australia have a disability and the majority are cared for at home. This systematic review aimed to determine the sleep obtained by parents of children with complex needs and/or technology dependence and the extent to which the overnight health or care needs of their child affected parental sleep experience and daily functioning.

Method

A mixed method systematic review based on 32 studies: 20 quantitative, 10 qualitative and 2 mixed methods.

Results and conclusion

Summary sleep length statistics were not possible due to the heterogeneity of included studies, particularly variability in sleep lengths within and between studies. But common themes that emerged are that the sleep deprivation experienced by these parents is relentless and draining and impacts on the parents and their relationships. The degree of sleep deprivation varies by diagnosis, but a key contributing factor is the need for vigilance at night. The evidence suggests that parents do not receive adequate support to care for their child with complex needs overnight.

Take home message

Advances in technology and recognition that home is the preferred site of care means that increasing numbers of children with a range of conditions and health care needs are being cared for primarily by parents in the home environment. While recognising the positive benefits this may bring, nurses need to be aware of the disruption to parental sleep patterns due to caregiving demands and the impact this may have on the parents' ability to function; learn complex tasks; and provide ongoing care.

The night shift: sleep deprivation in parents caring for children with complex needs

Damhnat McCann

Most children with complex needs are cared for at home, with benefits for the child & family, but often placing a significant burden of care on parents, particularly when overnight care is required.

Aim

To determine the sleep obtained by parents of children with complex needs & the impact of child care related sleep disturbance on daily parental functioning.

Methods

Mixed method systematic review. Quantitative papers included if sleep length measured (time sleeping or awake overnight). Qualitative papers included if sleep or night care was a theme in findings, or primary focus of related theme.

Analysis: narrative synthesis (quantitative); framework analysis (qualitative); segregated design (mixed method).

- 32 studies: 20 quantitative, 10 qualitative , 2 mixed method

Results

Average sleep length 4.5hrs - 8.3hrs/night (extreme variability within & between studies). Parents of children with complex needs have less sleep than normative population. Sleep deprivation main theme in all qualitative studies, affecting parents emotionally & physically, resulting in impaired daily functioning & altered work & sleeping arrangements.

- Time awake overnight ranged from 9mins to 2.6hrs. Certain conditions were associated with higher sleep disturbances (eg. eczema, seizure disorders, technology dependent).
- Vigilance (monitoring child's condition or behaviour) was a commonly reported contributor to sleep disturbance in addition to provision of health related & other night cares.

Conclusions

The sleep deprivation experienced by many parents of children with complex needs is relentless & draining. It varies with different diagnoses & care requirements, but the need for vigilance overnight is a common contributing factor. Parents do not receive adequate support to care for their children with complex needs overnight.

UTAS
School of Nursing & Midwifery

PhD supervisors: Professor Rosalind Bull, Associate Professor Tania Winzenberg

11.10 Appendix 10: Conference paper – Australasian Housing Researchers' Conference (Fremantle) 2013

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